CALIFORNIA DEPARTMENT OF HEALTH SERVICES
OFFICE OF AIDS
and
THE CALIFORNIA ALL-TITLES PLANNING GROUP

NOVEMBER 2001
STATEWIDE COORDINATED
STATEMENT OF NEED

2001 CALIFORNIA STATEWIDE COORDINATED STATEMENT OF NEED (SCSN)

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I. INTRODUCTION: WHAT IS THE CALIFORNIA COORDINATED STATEMENT OF NEED?

The complex continuum of HIV care and treatment services in California is funded through a wide range of public and private programs and resources. A large percentage of HIV care and treatment support, however, originates from **federal funding sources.** One of the most critical of these resources - particularly in terms of care and treatment for low-income and uninsured persons - is the **Ryan White Comprehensive AIDS Resources Emergency (CARE) Act,** a multi-faceted federal initiative designed to meet the emergency needs of persons living with HIV/AIDS who have limited financial resources. This Act is administered through the **US Health Resources and Services Administration (HRSA).**

The Ryan White CARE Act allocates funding through a series of **Titles**, each of which has its own set of parameters and requirements. The various Ryan White Titles support an array of services ranging from basic medical and psychosocial care, to innovative approaches to reaching and serving HIV-affected populations. At the present time, California has **54** separate CARE Act grantees, including **9** Title I grantees, **1** Title II grantee (the State of California), **20** Title IIIb grantees, **4** Title IV grantees, **14** Part F Special Projects of National Significance (SPNS) programs, **6** Dental Reimbursement Programs, and **1** AIDS Education and Training Center (AETC) grantee. Each grantee and region conducts its own local needs assessments on a broad range of care and service issues.

The purpose of the Statewide Coordinated Statement of Need (SCSN) is to bring Ryan White-funded providers together to integrate the findings of their various needs assessments, and to identify significant cross-cutting issues and challenges confronting HIV service provision in California. The SCSN document also includes a set of overarching goals designed to guide the future of HIV/AIDS planning and service delivery in each state.

While the various funding streams of the Ryan White CARE Act allows for a diverse range of approaches to meeting community needs, it also results in a situation in which Ryan White grantees do not always have a chance to communicate with one another, or to coordinate programs and planning to ensure consistency across the system.

In order to address this gap, in 1997, the US Health Resources and Services Administration enacted a legislative mandate requiring that CARE Act grantees collaboratively develop a **Statewide Coordinated Statement of Need (SCSN)** every three years. The purpose of the SCSN is to bring Ryan White-funded providers together to integrate the findings of their various needs assessments, and to identify significant cross-cutting issues and challenges confronting HIV service provision. The SCSN document includes a set of overarching goals designed to guide HIV/AIDS planning and service delivery in each state, and to help prioritize needs across the spectrum of CARE Act-funded services.

California produced its first Statewide Coordinated Statement of Need in March 1998, following a collaborative process involving representatives of all Ryan White CARE Act

grantees, as well as a broad range of consumers representing both rural and urban areas. This process proved highly successful, and formed the basis for development of the second SCSN in 2000-2001.

It is important to understand that the SCSN is not a policy document, and is not intended to prioritize or rank HIV/AIDS needs within the state. Rather, the SCSN provides a unique opportunity for consumers and providers to prepare a **compilation of HIV/AIDS issues and needs** which summarizes current and emerging trends in the epidemic, and which brings together the diverse perspectives of consumers and providers from **all** levels of involvement in HIV/AIDS services and care. No one recommendation or issue in the SCSN should be viewed as being more important than another, and not all issues will be relevant to every provider or consumer. The SCSN is designed to offer a **vision or ideal** of where the system of HIV/AIDS care in California should be headed, rather than a road map or blueprint for implementation.

In addition, while we have attempted to categorize issues and recommendations which share a common theme under specific title headings, many issues in the HIV/AIDS epidemic overlap or are inter-related, and cannot be summarized in one section alone. For this reason, we have provided an **index** at the conclusion of this document that lists each instance in which a specific service category or population is mentioned, so that readers can trace references to specific care areas.

The SCSN is <u>not</u> a policy document, and is <u>not</u> intended to prioritize or rank HIV/AIDS needs in California. Rather, the SCSN provides a unique opportunity for consumers and providers and consumers to prepare a compilation of HIV/AIDS issues and needs which summarizes current and emerging trends in the epidemic, and brings together the diverse perspectives of consumer and providers from all levels of involvement in HIV/AIDS services and care.

We hope that the 2001 version of the SCSN will serve as a valuable resource to help guide and support the continued development of an ever-improving system of HIV/AIDS care, treatment, and services for California. We also hope the document will assist planners and program developers to identify ways in which their own local needs and issues dovetail with issues at the statewide level. Please feel free to contact the State of California Office of AIDS - or any local Ryan White grantee agency - if you have suggestions or comments for improving future versions of the California Statewide Coordinated Statement of Need.

II. HOW THE CALIFORNIA SCSN WAS PREPARED

Because of its size, diversity, and complexity, preparation of a comprehensive Statewide Coordinated Statement of Need presents a special challenge for California. Our state has **61** separate health jurisdictions and **54** separate CARE Act grantees, each of which conducts its own local needs assessments on a variety of care and service issues. The first requirement for our process was therefore to devise a system for bringing representatives of **all** of these grantee organizations together to identify common needs, issues, and goals.

California responded to this challenge by forming a statewide planning group in early 2000 consisting of **one** representative from each Ryan White CARE Act grantee. In some cases, agencies and jurisdictions held more than one Ryan White contract, in which case one representative was appointed to represent all of an agency's CARE Act contracts. This group - dubbed the **All Title Committee** - began its planning activities through a series of **monthly conference calls** in early 2000, including designing a timeline and procedure for completing the SCSN in 2001. Because of its role as the largest single CARE Act grantee in California, the State Office of AIDS took primary leadership for the coordination and logistical management of these activities.

Because of its size, diversity, and complexity, preparation of a comprehensive Statewide Coordinated Statement of Need presents a special challenge for California. Our state alone has 61 separate health jurisdictions and 54 separate CARE Act grantees, each of which conducts its own local needs assessments on a variety of care and service issues.

One of the Committee's first tasks was to identify and hire a technical writer to assist in coordinating the SCSN process, and to compile findings and write and edit draft and final versions of the document. Because participants recognized that the SCSN was a **collaborative** document, a decision was made to divide the technical writer's fee among the State's 54 Care Act grantees, with the amount of each grantee's contribution based on the total annual amount of Ryan White funding granted to that agency. In this way, California could ensure a document that represented a true investment on the part of **all** Ryan White grantees in the State.

The second priority of the 2001 SCSN process was to increase participation of consumers of HIV/AIDS care and treatment services in giving guidance and input to the content of the document. While consumer input had been solicited for the 1998 version of the California SCSN, this input was **significantly expanded** for the 2001 document. A decision was made to sponsor **five separate four-hour consumer focus groups** in locations throughout the state of California, encompassing both rural and urban areas, as well as the widest possible range of cultural, gender, and language groups. These consumer focus groups - coordinated and funded by the California State Office of AIDS - were attended by an average of **16 participants each**, and provided significant new insights and information that greatly enhanced the relevance and usability of the SCSN document. All focus group sessions were tape recorded, and consumer input was transcribed for inclusion in this document

The five focus groups sponsored in conjunction with the SCSN were as follows:

Consumer Forum # 1:	**Fresno**	**October 4**
Consumer Forum # 2:	**San Francisco**	**October 12**
Consumer Forum # 3:	**Eureka**	**October 25**
Consumer Forum # 4:	**Long Beach / Los Angeles**	**November 1**
Consumer Forum # 5:	**San Diego**	**November 13**

From the perspective of Ryan White grantees in California, the primary vehicle utilized to obtain information from providers was a **statewide questionnaire** that sought input in a broad range of categories related to the purpose and content of the SCSN. Each Ryan White grantee was asked to complete this questionnaire, which provided input into issues, needs, and goals related to HIV/AIDS care in California. A total of **30** completed questionnaires were received and incorporated into the SCSN document. Agencies responding to the questionnaire are listed below, along with their location and Ryan White Title grants:

In order to expand consumer input into the 2001 SCSN, the California Office of AIDS coordinated five separate four-hour consumer focus groups in locations throughout the State encompassing both rural and urban areas, and the widest possible range of cultural, gender, and language groups. A statewide questionnaire for Ryan White grantee agencies was also completed by 30 separate agencies, providing key input into issues, needs, and goals related to HIV/AIDS care in California.

1. Alameda County Department of Public Health, Office of AIDS
   Oakland
   Title I

2. Altamed Health Services
   Los Angeles
   Title III

3. American Indian Health Services
   Santa Barbara
   SPNS

4. Clinica Sierra Vista
   Bakersfield
   Title III

5. Community Medical Centers, Inc.
   Stockton
   Title III

6. County of Sonoma Dept. of Health Services, Center for HIV Prevention & Care
   Santa Rosa
   Title I

7. Harbor - UCLA Medical Center
   Torrance
   SPNS

8. L.A. Gay & Lesbian Center
   Los Angeles
   Title III

9. Larkin Street Youth Center
   San Francisco
   Title IV

10. Los Angeles County Department of Health Services Office of AIDS Programs
    Los Angeles
    Title I

11. Los Angeles Family AIDS Network
    Los Angeles
    Title IV

12. Lutheran Social Services of Northern California
    San Francisco
    SPNS

13. Mendocino Community Health Clinics, Inc.
    Ukiah
    Title III

14. Mission Neighborhood Health Center, Clinica Esperanza
    San Francisco
    SPNS

15. North County Health Services
    San Marcos
    Title III

16. North Park Family Health Center
    San Diego
    Title III

17. Northeast Valley Health Corporation
    Panorama City
    Title III & SPNS

18. Orange County Health Care Agency
    Santa Ana, CA
    Title I & Title III

19. Pacific AIDS Education & Training Center
    San Francisco
    AETC

20. Russian River Health Center
Guerneville
Title III

21. Sacramento County Department of Health and Human Services
Sacramento
Title I

22. San Bernardino County Department of Public Health
San Bernardino
Title I & Title III

23. San Diego County Office of AIDS Coordination
San Diego
Title I

24. San Francisco Department of Public Health
San Francisco
Title I

25. San Francisco Community Clinic Consortium
San Francisco
Title III

26. Santa Cruz County Health Services Agency
Santa Cruz
Title III

27. St. Mary's Medical Center, CARE Program and Clinics
Long Beach
Title III

28. University of California San Diego, Mother, Child & Adolescent Health Program
San Diego
Title IV

29. University of California San Diego Medical Center, Owen Clinic
San Diego
Title III

30. Venice Family Clinic
Venice
Title III

Questionnaire responses and consumer focus group findings were compiled into an initial draft of the Statewide Coordinated Statement of Need, which was distributed to All Titles committee members and reviewed and revised both at a full-day meeting in Burbank on May 1, 2001, and a subsequent statewide conference call on May 15, 2001. A revised and

expanded version of the SCSN was then circulated again among All Titles Committee members and reviewed at a final conference call held on July 12, 2001. The current version of the SCSN incorporates all revisions made in that final conference call.

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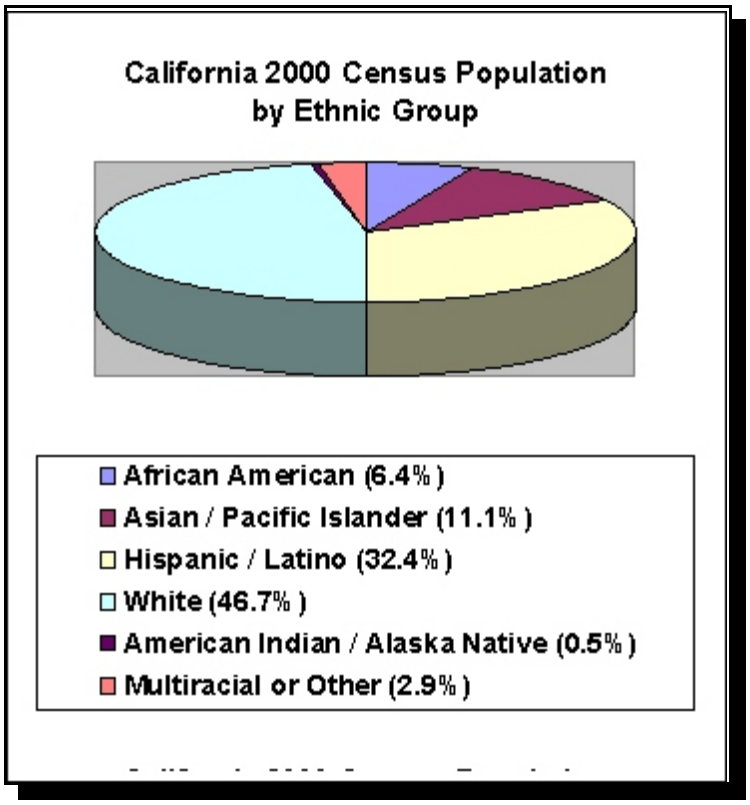
III. OVERVIEW OF CALIFORNIA AND ITS HIV/AIDS EPIDEMIC

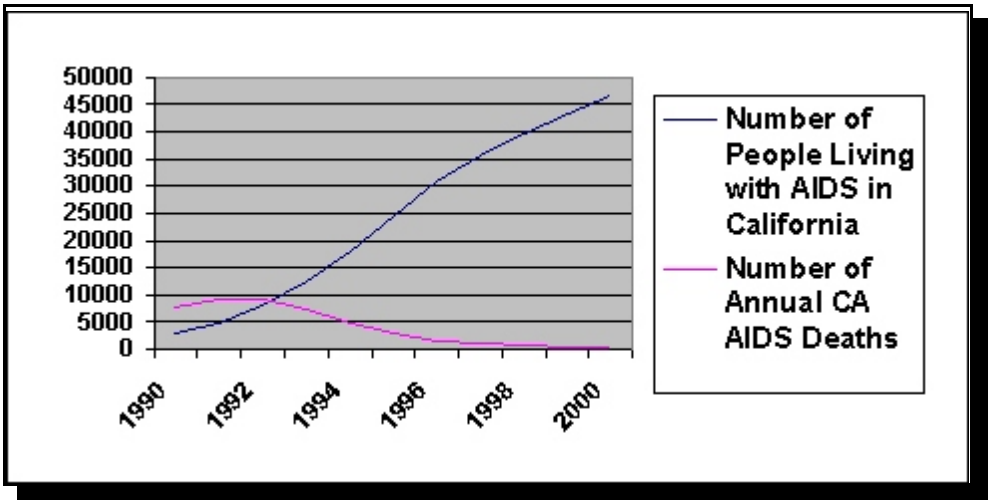
The state of California – diverse, complex, and geographically vast – is a region that encompasses literally hundreds of distinct living environments, cultural milieus, and urban and rural areas. The counties that make up California cover a total land area of over **163,00 square miles**, embracing deserts, mountains, forests, coastland, and farmland. From major cities, to suburbs, to rural and agricultural communities, to frontier and border regions, California is not one state, but many states, and cannot be defined by any single set of characteristics, norms, or sociodemographic features.

Recently-released 2000 Census results confirm that California remains by far the largest state in the nation, with a total population of **33,871,648**, a nearly **10%** increase over 1990 Census figures. **The state's population growth over the last decade alone was greater than the individual population of nearly half the states in the union.** Six of the 16 most populous counties in the United States are located in California, as are three of the nation's six most populous counties. This includes the largest county in America by population – Los Angeles County with **9,519,338** residents – and the largest county in America by land area – San Bernardino County, covering **20,062** square miles. Nearly **1 in 8** Americans – or **12%** of the nation's total population - call California home.



Confirming the expanding cultural diversity of California is the fact that ethnic minority communities now constitute the majority of California's population, according to the 2000 Census. Census figures reveal that whites now make up just under **47%** of the state's total population, versus nearly **75%** of the population a decade ago. Spearheading the State's vibrant cultural growth has been a **43% increase** in the state's Asian/Pacific Islander population, and a **33% increase** in Hispanic/Latino communities. California is by far the most culturally diverse large state in America, with a population that is **53%** ethnic minority including **32%** Hispanic/Latino, **11%** Asian/Pacific Islander, **6%** African American, **3%** multiracial, and **1%** Native American or Alaska Native. Nearly **one-third** of Californians now speak a language other than English at home, and nearly **750,000** officially recognized refugees, originating from all corners of the world, make their home in California. In addition, nearly **1 in 3** Hispanics in

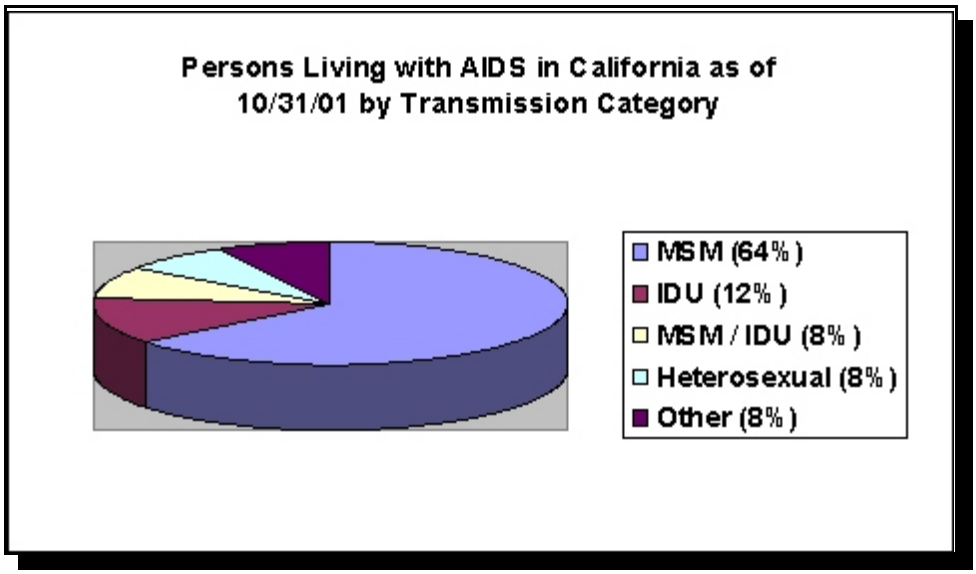
the nation live in the Golden State, and more than **43%** of all Californians younger than 18 are Hispanic, compared with **35%** a decade ago.

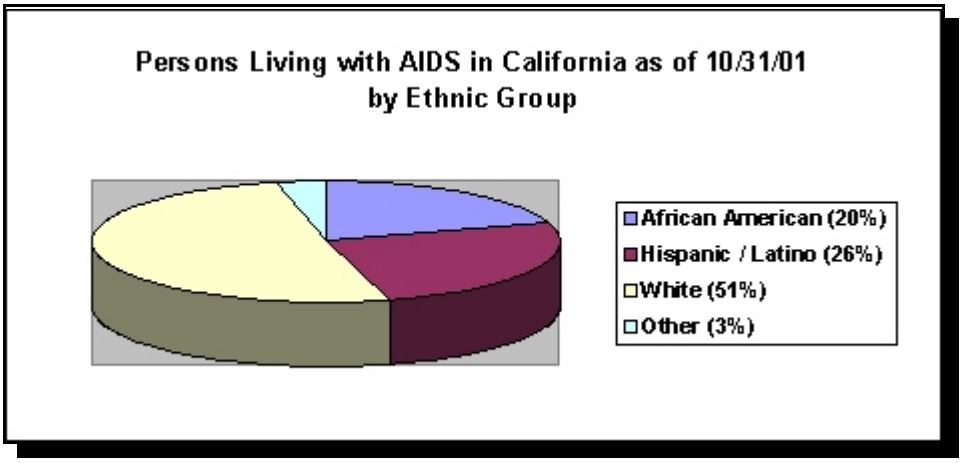


The size and diversity of California continues to be reflected in the scale and scope of its HIV/AIDS epidemic. As of March 31, 2001, a cumulative total of **120,121** cases of AIDS had been diagnosed in California, or approximately **15%** of all AIDS cases ever diagnosed in the United States.

As in virtually every other jurisdiction in America, California has continued to benefit from the stunning effectiveness of combination drug therapies in reducing both the rate of progression from HIV to AIDS, and the overall death rate of HIV-related illness. Yet although the number of deaths from AIDS and the rate of new AIDS diagnosis has declined each year since 1995, the number of people living with AIDS in California has continued to increase steadily. As of the end of October 2001, a total of **45,329** Californians were living with advanced HIV disease diagnosed as AIDS. This means that **nearly 1 in every 7 Americans living with AIDS now resides in California.**

Of course, these statistics do not include persons who have been infected with HIV but not been diagnosed with AIDS. A report issued by the State of California in January 1997 projected that as many as **130,500** Californians could already be living with HIV or AIDS. **If this number was applied to California's current estimated population of 33.9 million, it would mean that approximately 1 in every 260 Californians is now living with HIV or AIDS.**

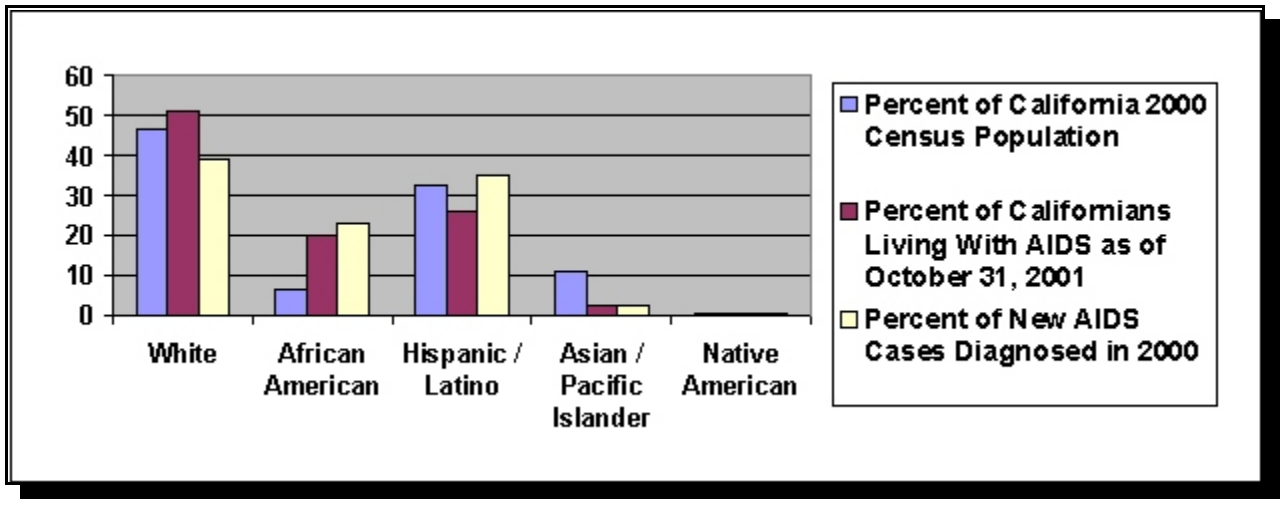




Despite changes in the characteristics of groups affected by AIDS, the AIDS epidemic in California continues to have disproportionate impacts on men who have sex with men. As of June 30, 2000, nearly **80%** of all adult California AIDS cases had occurred among men who have sex with men, including men who have sex with men and inject drugs. By contrast, these same groups made up only **53%** of the cumulative national AIDS caseload as of the end of June 2000.

People of color in California also continue to be heavily impacted by the HIV/AIDS epidemic, and their proportion within the overall AIDS caseload is increasing. In 1988, for example, people of color made up **less than 30%** of all new AIDS cases reported that year. By 1997, the **majority** of new annual AIDS cases were occurring among ethnic minority populations, and by 1999, the percentage had grown to **55%** of all new AIDS cases.

HIV/AIDS in California continues to have an expanding impact on African-American and Hispanic communities. Twenty percent of all persons living with AIDS in California as of October 31, 2001 were African Americans, while **26%** were Hispanic. While



most ethnic groups, including Latinos/Latinas, Asian/Pacific Americans, and Native Americans continue to be **under-represented** in relation to their numbers within the overall California population, African Americans are significantly **over-represented** in relation to the general population. However, among those diagnosed with AIDS in 2000, the percentage of new Latino/a AIDS cases increased significantly, and was nearly equivalent to this group's proportion within the overall California population.

Within African-American communities in particular, women make up a much larger percentage of persons living with AIDS than among Latinos/Latinas or whites. Fully **38%** of all women living with AIDS in California are African Americans, versus only **17%** of men.

Due to California's immense size and diversity, the incidence and demographics of HIV/AIDS can vary dramatically from county to county. This means that no one approach or system can apply to the entire state, and that each region or jurisdiction has distinct service and prevention needs in order to respond to its specific population.

In San Francisco County, for example, approximately **85%** of all adults living with AIDS as of October 31, 2001 were men who have sex with men - including men who have sex with men and inject drugs - while only **11%** were persons who had become infected through injection drug use only. Yet in Contra Costa County - located just across the San Francisco Bay - only **60%** of cases occur among both categories of men who have sex with men, and **24%** of living AIDS cases resulted from injection drug use alone - more than double the percentage in San Francisco.

Meanwhile, in Los Angeles County, only **39%** of persons living with AIDS as of October 31, 2001 were white, while in adjacent Orange County to the south, fully **59%** of persons living with AIDS were white.

AIDS Cases, Cumulative Incidence, & Ethnic Representation in California Counties

Counties with the Largest Numbers of People Living with AIDS as of 10/31/01

1. Los Angeles County - 16,249
2. San Francisco County - 7,944
3. San Diego County - 4,740
4. Orange County - 2,749
5. Alameda County - 2,444
6. Riverside County - 2,264
7. Santa Clara County - 1,356
8. Sacramento County - 1,233
9. Contra Costa County -805
10. San Mateo County - 726

Counties with the Highest Incidence of People Living with AIDS Per 100,000 Population as of 10/31/01

1. San Francisco County - 754.34
2. Marin County - 270.40
3. Alameda County - 161.59
4. Los Angeles County - 158.12
5. San Diego County - 156.90
6. Solano County - 154.87
7. Riverside County -139.10
8. Sonoma County - 132.93
9. Lake County - 99.87
10. Sacramento County - 99.67

IV FINDINGS, PART I: CROSS-CUTTING SERVICE GOALS

Introduction

When California's first Statewide Coordinated Statement of Need was produced in 1998, we believed it was critical to point out that the **size and diversity of the state of California presents unique and daunting challenges to planners of HIV care and services.** Today, that fact remains truer than ever. Over the past three years, California has become an even larger, more diverse, and more culturally rich state, and - as in our previous SCSN - HIV/AIDS programs in California still must be designed to serve exceptionally varied groups and communities with specifically targeted programs, while reaching large populations in urban and suburban areas, and far-flung populations in rural and frontier communities. Programs in California must also overcome divisions brought about by geopolitical boundaries or distance and by health jurisdictions, while simultaneously forging collaborations so large and complex that consensus-building often occupies a great deal of provider time. Programs must also serve communities and groups that have widely differing needs, while linking and integrating these services among a wide variety of public and private sector providers. The high level of poverty in which many Californians with HIV live further complicates the struggle to deliver effective, comprehensive services.

> ***"Things have changed dramatically for me, and for all of us in this epidemic. It's not the way it was four years ago, five years ago. And our needs have changed. But you know what? What's being offered to me hasn't changed very much...There was a time when we needed help desperately. But now most of us, on some level, can take care of ourselves if we're given the tools to do it. That's what I want. That's what my need is....I don't want someone to drive me anyplace. I want the drugs that will make me healthy enough to do those things myself. I don't want to decide if I see a doctor and when I see a doctor. I want to decide what meds I will take. I don't want somebody telling me, "No, you won't be able to adhere to this schedule, trust me, you shouldn't have protease inhibitors." I want to make those decisions for myself. The doctor is an employee, he's not your boss. The medical system is here to work in partnership with me; that's how I get my health needs met, not by telling me what to do."***
>
> - Mark, Person Living with HIV
> Quoted in First California SCSN, 1998

California's success in meeting and overcoming many of these challenges has led to a series of comprehensive care systems that meet <u>many</u> of the basic fundamental health and psychosocial needs of persons living with HIV/AIDS in our state. Over the past three years, we have made significant progress in ensuring that access to basic medical services and new combination drug therapies are available to all Californians who request them, and that basic medical services are linked to a network of supportive services that help meet the physical, emotional, and practical needs of people living with HIV/AIDS. We have also

ensured greater access to services for a wider range of emerging populations, and have successfully expanded outreach that has brought new individuals and families into treatment earlier.

But for California, the mark of progress achieved nearly always remains only a benchmark against which to measure future accomplishments. We still have a long way to go in guaranteeing full access to all needed services for all Californians affected by HIV, and we have much work to do to ensure that all residents of our state have access to services that consistently meet their cultural, linguistic, and lifestyle needs. Significant gaps remain in our system of care, despite our best efforts, and much work remains to be done in developing new approaches to integrating services; maximizing resources; bringing people with HIV who are aware and unaware of their serostatus into care; and attaining HRSA's goal of 100% access and 0% disparity in the provision of services statewide.

Yet as noted in our last Statewide Coordinated Statement of Need, if the culture and diversity of California makes this a challenging place in which to forge and implement an effective system of services, then the range, depth, and complexity of our populations also make it an ideal site in which to develop creative and effective service models that respond to a diverse human community. If HIV has brought struggle and tragedy to California, it has also brought a unique spirit of community, enterprise, and partnership to the fight to conquer it. We hope the following document will illuminate some of the critical ways in which our state continues to face the most important challenges that lie ahead, while developing new ways to meet and overcome those challenges.

> ***"HIV is a very tricky, challenging disease. It leads you to think you're doing okay one day, and then crosses you up the next."***
>
> - Bill, Person Living with AIDS,
> Long Beach Consumer Focus Group

The following is a **non-prioritized** list of broad proposed goals for HIV/AIDS care and services in California over the coming years, based on findings that have a broad consensus among HIV/AIDS providers and persons living with HIV/AIDS throughout the state.

Overarching Care and Service Goals:

- Ensure that all persons living with HIV in California receive all services necessary to sustain and support their health and quality of life, regardless of income or ability to pay, and across all stages of illness, by maintaining and enhancing the State's community-based system of HIV/AIDS care for men, women, transgenders, children, and young people.

- Ensure that HIV/AIDS services in California are delivered in an equitable, client-centered manner, and that services respond sensitively and appropriately to client age, gender, cultural group, primary language, sexual orientation, income, region or residence, family status, health status, incarceration status, and legal residency status.

- Ensure that HIV/AIDS services in California are delivered by experienced, competent, and fully trained providers who are knowledgeable about and responsive to their communities, and who understand and represent - to the extent possible - the cultural, linguistic, and lifestyle backgrounds of the clients they serve.

- Ensure and protect the confidentiality of all persons with HIV and AIDS in California, particularly as reporting requirements related to HIV and AIDS diagnosis change in the future.

- Develop and implement programs that end social isolation among persons living with HIV/AIDS, and that empower persons with HIV/AIDS to take greater a greater role in influencing and controlling the quality of their lives and health care.

- Expand the participation of persons living with HIV at all levels of HIV/AIDS planning, needs assessment, systems design, service implementation, and evaluation in California; and enhance opportunities and incentives for this participation. Ensure the participation of members of specific populations - such as women, young people, and people of color - in the development of services geared to these populations. Provide people with HIV/AIDS with the skills necessary to effectively contribute to local and regional planning and implementation processes, including making leadership training and technical assistance available on an ongoing basis.

- Support the continuation of locally based HIV/AIDS planning within the widest possible scope of Health Resources and Services Administration (HRSA) eligible service categories available to local jurisdictions and agencies. Each HRSA category fills a valid unmet need somewhere in the State's service delivery system and should be maintained in the continuum of care for California.

- Support the development of integrated and interdisciplinary models of care to ensure greater coordination between the primary care provider, specialty providers, and case management and psychosocial services professionals.

- Encourage integration of local planning and collaboration among all CARE Act Grantees and other public and private funders in order to ensure maximization of available resources and development of a comprehensive continuum of care within each region.

- Increase data collection efforts and approaches that allow us to better assess the quality of care provided to persons living with HIV/AIDS, and to better document the outcomes and impacts of HIV care and service provision on the lives and health status of persons living with HIV/AIDS.

- Conduct ongoing research to identify and determine the service needs of those not in care.

- Ensure that new advances in HIV-related treatment and care are quickly and continually incorporated into the care received by people living with HIV/AIDS at the local level.

- Recognize that the existing system of HIV/AIDS care in California provides a model for the provision of community-based care in other health and social service areas, and that to assure equitable and quality care for all Californians, efforts must be made to raise other social issue and disease responses **up** to the level of HIV/AIDS, and not **down** to a lower common denominator in which individuals do not receive the proper levels of community-based care, support, advocacy, and assistance they need and deserve.

Case Management Services:

- Improve the quality of service access and coordination for persons living with HIV/AIDS by increasing the professionalism, relevance, comprehensiveness, and client sensitivity of case management services at all levels of care, and by expanding efforts to create and support integrated case management systems and definitions throughout California. Maximize the effectiveness and minimize the duplication of case management services throughout the state. Reorient case management in relation to new drug therapies; expand case manager training and education; ensure greater consistency in staffing; recruit greater numbers of self-disclosing HIV-positive and other peer case managers; reduce unreasonable client caseloads; and facilitate greater integration and consolidation of regional case management systems among social and medical service agencies.

Changing HIV-Affected Populations:

- Examine the ways in which the existing system of HIV service and support will need to change or become more flexible to address those HIV-affected populations that are becoming more frequently affected, including HIV-affected women and single mothers, people of color, low-income individuals and families, injection drug users, young people, people in correctional settings, and residents of rural and frontier communities. Ensure ongoing flexibility in the location and scheduling of care and services for these and other populations.

- Examine the ways in which the HIV service system will need to evolve to confront the fact that many men and women with HIV and AIDS are living longer, and are requiring a distinct set of services – including long-term housing, basic job training, vocational rehabilitation, job placement, client education, insurance assistance, benefits advocacy, policy research, financial planning, and secondary prevention support – which is oriented toward helping them live longer, more productive, and more self-sufficient lives. Address the fact that the growing perception of HIV disease as a chronic, non-life-threatening illness is affecting both the availability of resources and the ability to sustain existing systems of care.

Children and Children's Issues:

- Ensure children's access to comprehensive and coordinated, family centered and developmentally appropriate HIV medical and support services. Ensure comprehensive developmental evaluations and interventions to promote learning, participation in school, and youth participation in medication adherence. Improve family-focused assessment skills and develop treatment plans for families.

- Promote community planning efforts for multisystem interventions for families. Increase the capacity of agencies serving adults to assess family needs and facilitate care for children. Advocate with health care systems for supportive mental health services for children affected by HIV. Help families plan for the future through education about and improved access to permanency planning.

Communities of Color Issues:

- Ensure the availability of culturally appropriate, community-based services for all communities of color affected by HIV/AIDS in California, including African-American, Hispanic/Latino, Asian/Pacific Islander and Native American populations. This includes expanding the number of people of color in direct care and service positions at all levels of care and service, and ensuring greater availability of care services directly within ethnic minority neighborhoods.

- Place a greater emphasis on expanding the availability and utilization of preventive care services by ethnic minority communities, who - because of economic, language, or residency issues - often utilize health care services only for critical or emergency care needs.

- Continue to address language and cultural barriers to care for people living with HIV/AIDS (PLWH) whose primary language is not English, particularly in terms of the severe lack of professional and paraprofessional providers who are bilingual in either English and Spanish or in English and one or more Asian/Pacific languages.

- Reduce barriers to HIV-related health care for Native Americans living both inside and outside of reservations, including expanding culturally competent care and support services in city-based facilities. Coordinate services wherever possible with care funded through the Indian Health Service of the Bureau of Indian Affairs.

- Continue to promote outreach to and collaboration with minority community-based organizations by mainstream systems and Ryan White-funded providers, particularly as these organizations serve as key entry points for bringing persons of color living with HIV/AIDS into the overall continuum of care.

Complementary Therapies and Treatments:

- Ensure access to high-quality, affordable complementary therapies and treatments that reduce the side effects of HIV medications, promote wellness, and reduce stress. Examples of such therapies may include: acupuncture, acupressure, herbal treatments, medical marijuana, massage therapy, fitness, aerobics, yoga, stress reduction, and/or relaxation techniques, with selection of treatments based on local regulations, agency programs, and identified client needs. Many PLWH choose to use complementary care in conjunction with Western medical care, and such care has been proven effective in many areas, including reducing the side effects of medication.

Consumer Migration and Mobility:

- Develop improved systems to better assess and respond to the extensive and continual migration that occurs **within** different regions of California, including between urban and rural areas, and within Hispanic/Latino and Asian migrant worker communities.

- Develop improved systems to assess and respond to the migration of new HIV-infected individuals **into** California from other states and nations. Promote the continuity of care for the US – Mexico border population, including both the transborder population that lives and/or works in the border area and continually travels between both countries, and the migrant population moving through the border region and throughout California.

Corrections Settings and Incarcerated Individuals:

- Ensure that **all** incarcerated individuals have immediate access to appropriate medical care, including referrals to specialists, pain management, diagnostic tests, and accurate information about their treatment options. Develop systems to ensure better accountability and higher quality health care within the California prison system, and to bring the quality of HIV/AIDS care and service in correctional settings at least to the level of community-based standards of care. Ensure that PLWH are able to take their medications as required, in coordination with meal schedules as needed, and that prison policies do not interfere with the ability for PLWH to take their medications. Ensure coordination of HIV services between different incarceration settings, and ensure continuity of care following prisoner transfers.

- Ensure the provision of transitional services with linkages to the community for PLWH being released from incarcerated settings. PLWH should always be released from prison with a supply of any prescribed medications, complete medical records, and linkages to all appropriate community services.

- Expand the participation of care providers under the supervision of the judicial system in HIV planning bodies in California, and ensure full access to combination therapies and compliance support in correctional settings.

Cultural Issues in HIV/AIDS Care:

- Continue to reduce service disparities by ensuring that HIV care providers relate to and understand the particular life choices, needs, and cultural backgrounds of their HIV-affected patients, and that they reflect - to the extent possible - the cultural, linguistic, and lifestyle backgrounds of the clients they serve.

Day Services and Respite Care

- Continue to expand the availability of day and respite care services throughout California, and expand the availability of licensed day care facilities, particularly in rural areas, as well as licensed, short-term drop off day care facilities at which PLWH can spend a day or afternoon with no prior notice required.

Dental and Oral Health Care Issues:

- Ensure the full available of adequate and comprehensive **oral health care services** for people living with HIV/AIDS across all regions and populations. Create a statewide mechanism for recruiting oral health dentistry fellows, and emphasize dentistry as a topic to be covered by the AIDS Education and Training Center's (AETC's) provider training activities. Make new funds available to expand and create new dental and oral health services for persons with HIV/AIDS through existing Ryan White Titles.

Direct Emergency Financial Assistance:

- Maintain the availability of direct emergency financial assistance services for low-income persons with HIV/AIDS, which offer a vital lifeline for individuals facing financial crises and temporary income shortfalls through one-time support that prevent homelessness and facilitate continuity of drug treatment therapy. This assistance is particularly important at a time of statewide energy crisis and rising energy costs.

Employment Development, Placement, and Training Issues:

- Support persons living with HIV/AIDS in their efforts to compete successfully for part-time, temporary, or full-time employment. Provide counseling, training, and other assistance needed to ensure job-related education, training, retraining, or trial work periods, applying federal guidelines if the individual is receiving disability benefits. Improve coordination among federal, state, and local government and private sector organizations that focus on habilitation, rehabilitation, and employment.

Food and Nutrition Services:

- Adequate food and nutrition services remain a critical and ongoing need for low-income persons living with HIV/AIDS in California, a need which increases as the population of PLWH becomes increasingly impoverished and in need of longer-term support and care. Ensuring access to high-quality foodstuffs - including high-calorie nutritional supplements, home-delivered meals, vitamins, and packaged and prepared foods - is essential for maintaining and prolonging the health status and life expectancy of persons

living with HIV/AIDS, and are a necessary pre-condition for ensuring the ongoing effectiveness of HIV-related treatment therapies. Food services must be comprehensively available in California to ensure both that **no** person with HIV/AIDS ever goes hungry. Both pre-packaged foods and prepared meals must also be available in forms fully consistent with dietary needs and restrictions, cultural preferences, and religious beliefs.

Harm Reduction Services:

- Increase the availability of **harm reduction services** at all levels – particularly **needle exchange programs** through which injection drug users have access to clean needles every time they use drugs. Fully incorporate harm reduction services into other HIV/AIDS service and care modalities, so that consumers are not unnecessarily lost to the system, and ensure a high quality of harm reduction services.

- Ensure that **active substance users** are fully supported in learning about and complying with complex drug regimens regardless of their current drug use profile, and ensure that they are provided with access to medical care, social services, and comprehensive treatment alternatives at all levels.

Hepatitis C:

- Strengthen the existing service system to better respond to the escalating epidemic of hepatitis C – including improved education, prevention, and testing - and link this system more fully to the existing HIV care system.

HIV Case Reporting and Confidentiality:

- As HIV case reporting becomes a reality in California, remain aware while that such reporting will improve our knowledge and understanding of trends in the epidemic, it will also provide us with data that is **only** specific to those who voluntarily seek HIV testing, and **not** a full or comprehensive picture of the full scope of the HIV epidemic in California.

- Ensure that as case reporting is implemented in California, consumers know that their name is not attached to HIV case reporting and that their privacy is being protected, including by developing new consent forms that clearly inform clients that their case of HIV infection **will** be reported if they test positive, and providing comprehensive information regarding all HIV services for which persons are eligible at the time of diagnosis.

Home Health Care Services:

- Home health care services are a vital link in the continuum of HIV/AIDS care, providing homebound persons living with advanced HIV disease access to high-quality personal care and monitoring, while helping maintain dignity and independence in the face of a debilitating, life-threatening illness. Special efforts must be made to ensure the availability of licensed home health care provider in the face of ongoing consolidation within the medical care industry.

Housing, Homelessness, and the California Energy Crisis:

- Ensure that persons with HIV/AIDS – including families affected by HIV – are able to access a comprehensive continuum of housing services and resources, with 100% access and 0% disparity, including emergency shelter, transitional housing, housing/rental subsidies, foster homes, congregate living facilities, skilled nursing facilities, board and care facilities, transitional housing for parolees and others released from prisons and detention facilities, and housing for people with multiple diagnoses. Ensure that HIV/AIDS housing is available in the least restrictive form desired by each individual. Develop strategies and technical assistance resources to help communities access additional housing resources for persons with HIV/AIDS. Encourage and provide incentives for local jurisdictions to utilize Community Development Block Grant funding, Department of Housing and Urban Development funding, and other housing funds as sources for building or converting low-income housing specifically for persons with HIV/AIDS. Expand integration with Healthcare for the Homeless grantees and with local housing authorities.

- Ensure that care services are reaching the homeless, especially those not in shelters or emergency housing. These men and women can be among the most difficult people with HIV/AIDS to reach, which means that additional efforts must be made in order to bring services to them, and to ensure that medical and other programs are fully accessible. Outreach and peer advocacy are essential components in this effort.

- Develop programs that respond to the crisis of rising energy costs in California. Recognize that these costs affect not only the ability of persons with HIV/AIDS to maintain adequate housing, but add to the operational burden and expenses for AIDS service organizations throughout the state.

Immigration Issues and Undocumented Communities:

- Ensure that comprehensive and culturally appropriate HIV/AIDS care and services are provided to **all** immigrant and undocumented persons in California regardless of their residency or migration status.

Insurance Benefit and Entitlement Issues:

- Ensure that persons living with HIV/AIDS are aware of **insurance benefits and other entitlements** for which they are eligible, and that they are provided with all needed assistance to access such benefits. Work to overcome key barriers to entitlement and benefits access, such as bureaucratic and confusing paperwork; uninformed agency staff; and fear of potential immigration status problems.

Legal Services:

- Ensure that people living with HIV/AIDS have full access to legal support and assistance services, including support with accessing benefits and insurance, combating and overcoming discrimination, and understanding their rights as employees.

Living Longer with HIV/AIDS - Issues Related to Long-Term Care

- Ensure that as persons with HIV/AIDS continue to live longer, healthier lives, that adequate medical attention and resources are focused on the **new health problems** beginning to emerge among these populations, including diabetes, lipodystrophy, heart disease, liver disease, manifestations of Hepatitis C, and preventive and restorative dental care. This includes health, psychological, and social impacts of **aging** as a person with HIV, including issues of isolation and lack of social interaction among older HIV-affected men who have sex with men. Provide expanded cross-training, education, and enhanced resources, and more information on medication interactions and metabolic complications. Ensure that care and treatment resources continue to be available at a level commensurate with the growth in the overall population of persons living with HIV/AIDS to be served.

- As longer lifespans create greater needs for **preventive health services** for persons living with HIV/AIDS, including an expanded emphasis on cardiovascular health, regular procedures such as breast and prostate exams, and ongoing patient health education in regard to non-HIV health needs. Provide greater levels of specialty care to meet increasingly complex patient needs.

- Expand the availability of **residential-based services** for persons living with HIV/AIDS who are very ill and who need the support of residential settings in order to start on anti-retroviral therapies with the hope of recovery.

- Expand opportunities for persons living longer with HIV/AIDS to participate in **community activities**, including more chances to socialize with others with HIV/AIDS, and more options to **volunteer**.

Managed Care and Medicaid:

- As private managed care providers are given more responsibility for caring for Medicaid beneficiaries, and as the prevalence of managed care systems in California expands, ensure that people with HIV/AIDS who are enrolled in these systems have access to the leading standards of care for HIV disease, and that the quality of care they provide is at

least equivalent to community-based standards of care outside of managed care settings. Require that managed care organizations provide geographically accessible, specialized, and experienced HIV/AIDS service providers for all persons with HIV. Require that a clearly understood and easily accessible consumer grievance system is in place within all managed care programs. Adjust managed care capitation rates or create "carve-outs" where needed to reflect the full range and frequency of higher costs of service provision for persons with HIV/AIDS. Ensure an adequate Medi-Cal capitation rate that includes drug treatment, outpatient medical and dental care, social services, and the risk of extreme inpatient care costs.

- Ensure continuation of Medicaid benefits for persons with HIV disease, and expand Medicaid in California to cover not only persons living with AIDS, but persons living with HIV who meet income criteria. Encourage the state of California to move forward with waiver requests and supportive legislation as both a humane and cost-effective approach to financing HIV/AIDS care.

- Ensure and enhance coordination between Medicaid and CARE Act systems, and between Medicaid and other systems of community care throughout California.

Mental Health and Counseling Issues:

- Ensure that persons with HIV/AIDS are able to access appropriate mental health treatment programs, including psychiatric consultation and psychotropic medications. Ensure that such services make use of existing mental health service systems, and that they include patient psychiatric care, community-based outpatient treatment, short and long-term therapy, crisis services, and residential treatment, in accessible and culturally appropriate modalities.

Multiple-Diagnosed Populations:

- Ensure the development and implementation of a comprehensive system for addressing the needs of multiple-diagnosed populations in California - particularly individuals affected by HIV and mental illness and substance addiction. Assure that the complex needs of these individuals are addressed so that they do not "slip through the cracks" as health systems focus more closely on cost efficiency and cost savings in light of managed care. Explore the possibility of integrated funding to support these services within a unified framework.

Peer Advocacy Services:

- Ensure the continued availability of peer advocacy services through which trained individuals provide direct service, support, and assistance to persons living with HIV/AIDS from comparable or compatible sociodemographic backgrounds. These services can help overcome the isolation and loneliness that often negatively impacts client health, while serving as a vital link to services and socialization.

Perinatal HIV Transmission:

- Ensure continued comprehensive HIV education for prenatal physicians to allow them to provide HIV education, testing, and interventions designed to reduce perinatal HIV transmission. Increase the capacity of labor and delivery sites to allow them to offer rapid testing to women who have not tested or sought prenatal care, and through obstetrical interventions designed to reduce mother to child transmission.

Poverty as a Public Health Issue:

- Address the fact that a growing percentage of HIV-related client needs and problems are rooted in poverty by developing effective methods to jointly address poverty and HIV issues in California. Increase opportunities to form and develop partnerships between HIV providers and poverty-related community groups and advocates in order to expand and deliver services for both populations.

Prevention for HIV-Positive Persons:

- Continue to develop effective and comprehensive prevention services for people living with HIV/AIDS. Ensure that such services are focused on empowering persons with HIV to protect themselves and others; that they are provided in culturally appropriate, respectful ways that take into account the emotional and mental health aspects of HIV/AIDS; and that they are coordinated with systems of care for persons living with HIV/AIDS. Ensure that while prevention messages and interventions are tailored to PLWH distinct and separate from prevention messages and interventions for negative individuals, they are nonetheless continually integrated and coordinated with HIV prevention efforts for HIV-negative individuals.

Primary Medical Care and Drug Therapies:

- Continue to make the availability of comprehensive, high-quality, and culturally competent primary medical care - with 100% access and 0% disparity - the first priority within the spectrum of Ryan White-funded care within the State of California.

- Ensure the universal availability and subsidy of all appropriate new and existing medications and drug treatment combinations, with 100% access and 0% disparity, for all eligible persons with HIV who are deemed medically appropriate and who wish to receive them.

- Support programs that help and empower clients to understand and adhere to complex medication regimens, in order to maximize the benefits these treatments can provide.

- Ensure continuing professional competence in prescribing and monitoring medications for persons living with HIV/AIDS, and in supporting patient adherence through pharmacy consultation programs, mandatory continuing education, professional training, the development and dissemination of continually updated clinical standards, and programs such as AETC that provide high-quality HIV-dedicated training to providers such as doctors, nurses, pharmacists, and dentists.

- Continue funding programs such as the AIDS Drug Assistance Program (ADAP), Medicaid, and the Children's Health Insurance Program (CHIP) that help subsidize the cost of medications. Continue to ensure these programs' wide accessibility to patients.

- Expand the number of candidates for combination therapy through relevant services such as substance abuse treatment, housing, transportation, and case finding, and provide services to support patient adherence at all levels.

Research and Clinical Trials:

- Include the broadest possible cross-section of populations affected by HIV/AIDS - including populations of color, adolescents and young adults, women, and injection drug users – in government-sponsored clinical trials programs, and expand the opportunities for persons with HIV from all economic, geographic, and cultural backgrounds to participate in clinical trials research. Support research on complementary and alternative therapies as an important strategy for exploring potentially promising new treatments for HIV disease. Continue and expand support for research into models of service delivery, models of evaluating effectiveness and efficiency in care delivery, models for ensuring greater client adherence to care appointments and to therapeutic regimens, and the importance of cultural responsiveness in improving client adherence.

- Increase opportunities for collaborative interaction between researchers and providers at all levels of care. This includes broadening channels for disseminating and sharing research findings at the community level, and for finding ways to better incorporate research findings into community-based planning and program development.

Rural Service Issues:

- Address continuing HIV/AIDS service deficiencies and barriers in rural areas, including lack of transportation, lack of skilled service providers, and a shortage of doctors, nurses, and other health care professionals qualified and trained in HIV care.

Service Integration and Coordination:

- Ensure the quality, scope, and coordination of care for persons living with HIV/AIDS in California by increasing the ability of providers to plan and develop collaborative, multi-disciplinary approaches to HIV service and care, especially in light of the changing, complex needs of those affected by the epidemic. Develop opportunities and incentives for increased interaction and service integration among providers and consumers, CARE Act grantees, HIV/AIDS and non-HIV/AIDS-specific agencies, local and regional health jurisdictions, medical and psychosocial providers, public and private funders, private and governmental bodies, local and national agencies, rural and urban providers, and local and regional consortia and planning groups.

Sexually Transmitted Disease (STD) Control:

- Establish HIV testing as a standard of care in all sexually transmitted disease (STD) clinics, and treat these clinics as key points of entry into the overall HIV/AIDS care system.

Substance Use and Addiction Treatment Services:

- Ensure the availability of substance abuse treatment programs for all persons with HIV/AIDS who wish to receive them, through a continuum of treatment options including residential (medical) and non-residential detoxification, short-term and long-term residential care, and outpatient services. Ensure the availability of supportive services that help individuals achieve success in substance abuse, including transitional and supportive housing for individuals leaving treatment, transportation, mental health services, and job training and placement. Expand substance abuse-related service integration and coordination among providers, as well as development of expanded transitional "after-care" programs for HIV-affected men and women in substance abuse treatment.

Transgender Service Issues:

- Include consideration of the special needs of transgender people living with HIV/ AIDS in the design of service programs, including but not limited to outreach, primary care, substance abuse, gender transition therapies, mental health, and housing services. Include representation of transgender individuals in epidemiological and data collection activities.

Translation and Interpretation Services:

- Translation and interpretation services provide an essential means for providers who do not speak the client's primary language – particularly medical care professionals – to listen to and learn from people living with HIV/AIDS, to and communicate important medical and support information that can enhance both the quality and length of patient life. Translation and interpretation services, however, must always be culturally specific, delivered by individuals who understand not only the patient's language or dialect, but also his or her specific cultural perspectives and background.

Transportation Services:

- Ensure full access to comprehensive transportation services for persons with HIV/AIDS, including access to a full range of transportation options, and subsidization of transportation costs, including transportation suitable and accessible to persons with disabilities other than HIV.

Tuberculosis Control:

- Establish HIV testing and counseling as a standard of care for all persons with confirmed or suspected cases of tuberculosis in California.

Women and Family Service Issues:

- Address the special and growing needs and problems of HIV-infected women and single mothers in California, including the need for expanded prenatal care and voluntary prenatal HIV testing to prevent perinatal transmission; increased child care and respite care resources; the potential adverse effects on women of welfare reform; the lack of competent medical advice regarding combination therapies; and the need for increased participation by women in clinical trials.

- Ensure that all California pregnant women have early access to HIV diagnosis and treatment - including retroviral therapy - along with strong protections of personal confidentiality and choice. Advocate for updated prenatal guidelines for pregnant women who may be living with HIV.

Young People and Adolescents:

- Ensure that as more and more **young people (18 - 24)** and **adolescents (13 – 17)** are affected by HIV/AIDS, specialized service continuums are developed and refined for both gay-identified and non-gay-identified youth, including non-traditional testing and outreach programs, and specialized medical care services and clinic times that are tailored to young people and are more easily and comfortably accessible. Also provide increased substance abuse services for young adults living with HIV; increased access to specialized mental health treatment services; increased availability of housing, transportation, and social support services; and increased support for young adults transitioning out of incarceration settings.

- As more **young people and adolescents** are being infected with HIV, expand efforts to encourage and facilitate expanded, voluntary HIV testing by young people. Provide **specialized prevention interventions** for young people living with HIV/AIDS that utilize approaches and systems distinct from those focused on HIV-positive adults.

V. FINDINGS, PART II: CURRENT AND EMERGING ISSUES, TRENDS, AND NEEDS

Introduction

The following list of cross-cutting issues – some broad and some focused – is intended to serve as an **outline** of many of the specific service issues which currently affect the scope and nature of HIV/AIDS delivery in California. Presented in alphabetical, rather than priority order, these categories highlight special circumstances, trends, and needs which participants in the SCSN process have identified as being of current or emerging importance to their work and service planning. Because our process has drawn from **two** sources of information – **1)** A series of consumer focus groups throughout the state; and **2)** Direct participation by Ryan White grantees in California through a comprehensive statewide questionnaire and subsequent review and revision meetings – sources for these items are generally cited either as "focus group participants" or as "respondents".

"My case manager told me recently that their agency had just gotten a call from a woman who said her husband was a hunter and had a bunch of deer meat and different kinds of things in the freezer, but they had lost their electricity and she was afraid the meat had spoiled so she didn't want to serve it to her family, So could she donate it to the food bank so persons with AIDS could have it? And I got this feeling like that spoke what she thought – that HIV people were just not worth as much as members of her own family. But that's an attitude that you often have to deal with."

- Mary, Person Living with AIDS
Fresno Consumer Focus Group

Our list of cross-cutting issues is interspersed with **three** additional categories of information, all of which are contained in text boxes on each page. The first set of information – contained in five different text boxes - summarizes key findings from our statewide consumer focus groups related to overall HIV/AIDS service and delivery issues in California. The second set of information presents excerpts from Ryan White grantee questionnaires that illuminate in greater detail emerging issues or critical service areas. The third category of information features descriptions of innovative cross-cutting service and planning initiatives that exemplify California's commitment to innovation and partnership in developing comprehensive continuums of care.

As with our last SCSN, please note that throughout this report, the highlighting or lack of emphasis on any specific Ryan White service category does not indicate or imply that a priority is being placed on one service over another, or that any CARE Act-funded service is in any way dispensable within the overall spectrum of HIV/AIDS services in California. As a document summarizing existing and emerging trends and needs, this statement necessarily focuses more on those issues that present the greatest **challenges** to providers and consumers, and which are currently under more focused or extensive debate within California's HIV/AIDS service community.

Overarching Service Issues and Needs

- Primarily because of the continuing efficacy of new drug treatments, people with HIV/AIDS in California are continuing to live longer and healthier lives. While this has brought about a welcome decline in the number of AIDS-related deaths, it also means that more people are living with HIV/AIDS than ever before, including both CARE Act consumers and all people with AIDS. Participants in our consumer focus groups noted that living **longer** with the disease did not necessarily mean living **better** with the disease. As one participant put it, "We're **staying alive** longer, not necessarily **living** longer." Another said, "We're no longer accepting a **death** sentence – we're accepting a **life** sentence. And that's not necessarily easier. In some places, in fact, it's much harder." Ensuring that a longer lifespan is a welcome change, rather than a daunting challenge, remains one of the key goals of California's Ryan White service system.

- The key overriding need among California's HIV/AIDS service providers is to ensure that CARE Act services are **available, accessible, and culturally** and **linguistically appropriate across all populations and service categories,** and that we come as close as possible to HRSA's ultimate goal of **100% accessibility / 0% disparity** in the provision of CARE services. This is both increasingly important and increasingly challenging as the population of CARE Act-supported people living with HIV/AIDS in California are **increasingly poor, homeless or marginally housed**, and **multiply diagnosed**.

- Providers note that the existing system of HIV service or support will need to change its expertise, staffing patterns, and way of doing business in order to effectively address the needs and increasing complexity of care for expanding HIV-affected populations such as **women and single mothers, people of color, families, low-income individuals**

Accessing HIV/AIDS Services in California: A Consumer Perspective Part I

When it came to the issue of ensuring **coordinated, comprehensive systems of care in local regions,** participants in the statewide consumer focus groups consistently spoke of the need to ensure **better coordination and integration** among service providers in their region, and of the need for CARE Act-funded programs to have better linkages directly within PLWH communities. Participants suggested that more extensive dialogues be conducted between state and local agencies to allow coordination across jurisdictions, and encouraged dialogues between, say, mental health and substance abuse providers, or between sickle cell and HIV specialists. Consumers consistently spoke of their frustration with the fact that HIV/AIDS providers too often seemed to function in a **vacuum or in a kind of parallel universe,** without significant interaction or integration with other disciplines, diseases, or service systems. This, they felt, resulted in an inability to fully respond to the full range of their health and service needs, and in unnecessary duplication or wasting of resources due to a lack of service coordination and integration.

and families, injection drug users, young people, people in correctional settings, and **residents of rural and frontier communities.** Each of these populations tends to access health care **later** in the disease process, and continues to face the **stigma** still associated with HIV/AIDS and HIV risk behaviors in society at large – a stigma that remains a barrier to accessing services and participating in the continuum of care. **Each affected population requires a specific, tailored, and uniquely comprehensive range of services in order to ensure an effective continuum of care that meet their full range of needs, and provide specialized and appropriate service access.**

- Providers also believe that capacity for **enhanced data collection across the entire system of care** must also be expanded in all regions of California, including across all Ryan White Titles and systems of care, and throughout the state of California as a whole. Expanded data collection will allow agencies and jurisdictions to more quickly and accurately identify service gaps and deficiencies; to produce meaningful data that allows for effective assessment of the quality, impact, and outcomes of services; and to plan resource allocation scientifically. Data collection should also be expanded to include reliable means of identifying and quantifying the number and nature of persons with HIV/AIDS who are currently being cared for within managed care systems. This goal is closely related to an expressed need for enhanced, standardized, systemwide **program and outcomes evaluation systems** that establish realistic, comprehensive assessments of services, and that allow for cost/benefit, utilization, and client outcome analysis throughout the system.

> ***"Case management is the "hub" of the wheel of services which enable clients with HIV/AIDS to access services. Case management is a collaborative process which plans, implements, coordinates, monitors, and evaluates options and services in order to meet individual needs in a timely and appropriate manner. Case management is also an ongoing process that works to empower clients who wish to participate in their plan of service or plan of care."***
>
> -Sacramento County Department of Health and Human Services Title I Response

Case Management Services

- The need for medical and social **case management** services remains central for persons living with HIV/AIDS. Case management ensures access to services; identifies and meets emerging and emergency needs; and empowers consumers to take greater control over their own lives and care plans. However, additional and expanded funding is continually needed to ensure that client to case manager ratios remain reasonable and manageable based on individual client acuity levels, and that qualified, sensitive personnel can be hired to fill case manager positions.

- There is a, however, a wide range of opinions and perspectives regarding the form that HIV/AIDS case management should take, including differences of opinion concerning the goals and intent of HIV/AIDS case management; the limits and functions of case management personnel; and the appropriate ratio of case managers to clients. What ties these versions together is agreement about the need to provide **coordinated care** to HIV-infected populations. However, regions that have multiple and sometimes overlapping case management systems must ensure appropriate and thorough **communication** in order to minimize duplication and coordinate case management systems to the greatest extent possible.

> ***"Right now in our community, we focus on giving service providers – primarily the gay white population – sensitivity training and what they call 'cultural competency' training, although I'm not sure you can ever really be culturally competent even within your own subgroups, but I think we need to change the term that we use. Instead of cultural sensitivity we need to start thinking about inclusion or unity training that includes everybody, getting within that training all the components that we need for all the special populations."***
>
> - John, Person Living with AIDS
> Eureka Consumer Focus Group

- Respondents note that there are often not enough resources available for either **case management** or **peer advocacy** services, both of which are still often not clearly defined, and which could serve as an effective hub for ensuring a comprehensive continuum of care, including linkages between primary care, medications, and supportive services. Respondents note that they lack the resources needed to implement new case management standards they have recently developed for their regions, while others note the lack of resources to ensure effective **ongoing training** of case management professionals, and to reduce problems caused by **high staff turnover** among case management personnel.

- A new approach to coordination of systems is needed to eliminate **duplication or repetition** of case management services among providers, and to ensure that client care plans are developed and monitored in conjunction with only **one** case manager for each consumer. Elimination of duplication could help reduce the confusion and frustration expressed by many of our consumer focus group participants, who spoke of frequently being passed from case manager to case manager; of being unsure of who their 'real' case manager was, or of preferring another case manager over the one to which they were assigned, but being unable to choose their case manager because of organizational regulations.

- As HRSA's emphasis on **quality management** expands, case management services are increasingly being seen as a service that is ideally suited to the provision of system-wide information on consumer needs and outcomes and on the overall effectiveness of systems of HIV-related care.

- Some respondents believe that our current definition of case management is too narrow, as it is frequently used to describe only services that provide referrals to consumers and that link them to service. However, for communities that have no or limited access to needed services, case management functions are often much wider, and include interventions such as counseling, education, and advocacy. To these respondents, case management definitions should be expanded to include the more traditional Medical Social Work model. Both of these versions are contrasted with 'gatekeeper' versions of case management in some private or for-profit systems of care, in which the function of client medical case management is sometimes to **restrict** or **limit** client access to services, rather than facilitate service coordination and access.

Promoting Innovative and Emerging Models of Care: The Street-Side Case Management Program

In the Sacramento EMA, Congressional Black Caucus funds are being used to support the **Street-Side Case Management Program**, designed to provide services immediately at the time of positive testing through a neighborhood clinic in a high-impact neighborhood. Using an integrated service delivery approach, a traveling "CARE-A-VAN" makes regular visits to corners and neighborhoods of known drug users, offering free STD testing and incentives to return for results. If diagnosed positive for HIV upon their return, consumers – nearly all of whom are African-American or Latino - are immediately given access to a case manager who provides them with counseling and transportation, and who assists them in obtaining needed social services and benefits. The clients are "fast-tracked" into medical care at Sacramento's HIV special care clinic, and the transitional street-side case manager immediately introduces them to their new regular case manager. The street-side case manager then follows the client's progress, assisting them with care until they feel comfortable enough with the regular case management system.

Children and Children's Issues

- Children are profoundly impacted by HIV. HIV-infected children need access to a full continuum of care, including prompt diagnosis, high quality treatment, and psychosocial and developmental services. In many communities, families face enormous challenges in accessing HIV services that are "family friendly" or responsive to the needs of children. In needs assessments, families identify many basic unmet needs including transportation, housing, food, child care, respite care, dental, primary care, legal and mental health services, and supportive services. Families continue to feel stigmatized, do not perceive family or community support and delay disclosure of HIV status. Barriers to care include lack of services targeting this population, inadequate bilingual staff, and limited information available about services.

- Thousands of children across the state live in vulnerable households, with one or more family members living with HIV. They are faced with demands of their parent's chronic

disease, multiple losses, unstable households, and shifting caregivers. Many families are also coping with poverty, substandard housing, substance use, mental health problems, incarceration, and domestic violence. Families frequently report that they have nowhere to go for support. Services for affected children are needed by the majority of families, yet are extremely limited. The current systems of primary health care for children have been unable to effectively respond to the needs of families living with HIV.

Communities of Color Issues

- A greater emphasis should be placed on expanding the availability and utilization of **preventive care services** by ethnic minority communities, who – because of economic, language, or residency issues - often utilize health care services only for critical or emergency care needs.

- Many consumer focus group participants spoke of a lack of services and programs specifically sensitive and responsive to **Latino communities** in California, particularly the lack of monolingual Spanish services and the lack of community-based services for very poor, migrant, or undocumented Latinos. These problems seemed to be multiplied for **Latina women**, who often said that **no** services of any kind were available to them within the specific community or region in which they lived.

- **Language and cultural barriers** create significant problems for PLWH whose primary language is not English, particularly in terms of the severe lack of professional and paraprofessional providers who are bilingual in either English and Spanish or in English and one or more Asian/Pacific languages. Consumer focus group participants pointed out that there were more than **100** different **Asian/Pacific languages, dialects, and cultures** in California, and that each had specific cultural needs and differences. These participants voiced their frustration with the fact that too often when California HIV providers used the word "bilingual" they meant bilingual only in English and Spanish. Such problems also relate to the lack of **multicultural staff** to address needs of diverse populations living with HIV/AIDS, particularly among physicians, mental health therapists, and case managers.

- **African-Americans** with HIV/AIDS repeatedly request culturally sensitive services, including support groups, outreach, and medical staff. Specifically, there is a need for more African-American **physicians and medical professionals**. This population also mentions a need for more services targeting **African-American women and children**; for programs that are built on assessments of community perceptions and needs; and for expanded involvement of community members in program planning and evaluation.

- Particular barriers to HIV-related health care exist for **Native Americans** living both within and outside of reservations. California has the largest population of urban-based Native Americans in the country, and culturally competent care and support services are desperately needed in city-based facilities. Services should also be coordinated wherever possible with care funded through the Indian Health Service of the Bureau of Indian Affairs.

- Another significant cultural issue relates to the reluctance many people of color say they feel about entering facilities that are clearly marked with signs saying, **"AIDS"** or **"HIV"**, particularly when these facilities are located within their own communities and neighborhoods.

- Because of their indispensable ability to provide culturally and linguistically appropriate care and services, outreach to and collaboration with **minority community-based organizations** by mainstream systems and by Ryan White-funded providers should be significantly expanded. This is doubly important because minority community-based organizations often serve as **key entry points** for bringing persons of color living with HIV/AIDS into the overall continuum of local and regional care.

Promoting Innovative and Emerging Models of Care: The HIV Latino Summit 2000

The **HIV Latino Summit 2000** was held on December 6, 2000, through the sponsorship of the State Office of AIDS and the Multicultural AIDS Resource Center of California. The Summit brought together **250** health professionals, advocates, and service providers from throughout the state, who examined critical issues in Latino health and HIV, including physical health, behavioral health, housing, access, and cultural and linguistic competence. The Summit also developed a series of policy recommendations to address the health needs of the California Latino community.

- The Centers for Disease Control and Prevention and HRSA's **Minority AIDS Initiative** provides vital new support for culturally appropriate outreach services among communities of color, services that should be coordinated and integrated with existing service programs for communities of color.

Complementary Therapies and Treatments

- Participants in the statewide consumer focus groups frequently cited the need for more extensive and reliable referrals to providers of **complementary therapies,** and for more extensive support for and subsidization of such services. Consumers believed that the network of complementary treatments should include - at a minimum- acupuncture, acupressure, herbal treatments, medical marijuana, massage therapy, fitness, aerobics, yoga, stress reduction, and relaxation techniques. As people with HIV live longer, there is a need to explore the effects of such techniques on health and well-being.

- The passage of the **medical marijuana initiative** in California - while currently being challenged in court - sent a clear message regarding the public's belief in the importance of medical marijuana being available to those with critical or life-threatening illnesses who can benefit from such treatment. Focus group participants and questionnaire respondents alike stressed the importance of so-called "pot clubs" within the overall spectrum of HIV/AIDS care.

> ***"I think we lack preventive services in the area of complementary therapies….I'm someone who's still grateful that I'm asymptomatic and have a job and have adequate medical care, but some of the things that are a financial burden to me are accessing complementary therapies that I believe keep me healthy, like massage, acupuncture, vitamins, things that we're finding out are an aid to dealing with some of the long-term side effects of the drugs. These things get expensive – you can spend over $200 a month on complementary therapies, and there's nothing in Ryan White that really addresses preventive stuff like that."***
>
> - Anthony, Person Living with AIDS
> San Francisco Consumer Focus Group

Consumer Migration and Mobility

- **Intra-state migration issues** are placing an increasingly significant stress on the existing system of care in our state. In some California cities experiencing a long-term housing crisis, low-income tenants are being forced out of affordable housing, and must move into less safe housing and neighborhoods. This can mean disconnection from services, support systems, and family members, and results in both increased financial and emotional stress. In some cases, PLWH are moving out of the largest cities and into supportive, somewhat less populous regions, such as Oakland, Fresno, or Palm Springs. In other cases, PLWH from rural areas with fewer services are moving closer to urban areas, with their relatively higher levels of care. And many individuals from outside the state move to California because of the enhanced services available for persons with HIV/AIDS. All of these situations in turn create an increased burden to care for these new affected residents. In addition, current reporting systems do not allow federally-defined Eligible Metropolitan Areas (EMAs) to know how many new persons with HIV/AIDS have moved into their regions over a given reporting period, and how many have left. This in turn creates barriers to completing accurate needs assessments, and may produce funding disparities among different CARE Act-funded regions.

- Providers located near the **US – Mexico border** note that the disproportionate share of resources between the US and Mexico creates challenges in providing continuity of care for a bi-national and highly mobile and migrant population.

Corrections Settings and Incarcerated Individuals

- While some progress has been made, services for persons with HIV/AIDS in **correctional settings** remain severely inadequate in many cases. Respondents who refer to this issue agree that prisoners have a constitutional right to appropriate medical care that is at least as high in quality as the services available within community settings, including referrals to specialists, pain management, diagnostic tests, medications adherence support, and ongoing education about treatment options. Physicians in correctional settings need training on HIV interventions and treatments. Respondents also stress the necessity of effective HIV risk-reduction materials, including condoms, being widely available in corrections settings in order to prevent new or cross-infections. While some providers believe that important steps to improve the quality of HIV/AIDS care in correctional settings have been taken, one consumer focus group participant said, "**Nothing** in the criminal justice system is HIV-friendly."

  "The state prison system fails to consistently provide high quality health care, especially to women and transgender inmates. The war on drugs has also caused disproportionate numbers of young people, people of color, and injection drug users to be incarcerated, and often fails to provide appropriate HIV prevention information and resources, including condoms and clean needles. Adequate substance abuse treatment is also lacking, and many inmates with HIV/AIDS are released without appropriate links or referrals to care in their community."

  - San Francisco Department of Public Health Title I Response

- As larger numbers of PLWH are being returned to the community due to jail and prison overcrowding, or transferred among different corrections settings, it is essential that **transitional services and support for parolees** be provided, including ensuring that prisoners are released or transferred with a supply of prescribed medications, and with appropriate linkages to internal or outside services. This support will require an intensive range of services that help prisoners find and maintain affordable housing; have access to transportation and food; and ensure their access to and retention in primary medical care and other care, including substance abuse treatment. The increased care burden on community-based HIV/AIDS organizations of recently-released individuals also needs to be recognized and subsidized.

- Consumers who have histories of **recent incarceration or poor credit** are frequently able to obtain only substandard housing. New regulations are needed to facilitate the entry of people with HIV/AIDS who have incarceration or poor credit histories into new housing opportunities.

Cultural Issues in HIV/AIDS Care

- A problem voiced loudly and often by consumer focus group participants involved the frequent **inability of some physicians to relate to or understand the particular lifestyles, needs, or cultural backgrounds of their HIV-affected patients.** Numerous focus group participants spoke of the tendency of some physicians and front-line providers to be **judgmental or critical** of personal lifestyle or behavioral choices, or to offer advice or treatment options that were **irrelevant or inapplicable** to the beliefs, background, or options available to the patient. Questionnaire respondents noted that **provider discomfort with sexuality** keeps many providers from communicating with and meeting the needs of their consumers, particularly in the case of prevention services and mental health services. Providers consistently need sexuality training to adequately serve all PLWH.

- While some of these problems might be addressed through expanded **cultural, language, or sexuality training** of primary providers, focus group participants and questionnaire respondents alike felt that a more viable way to address the problem would be through the **expanded recruitment of more diverse physicians and providers** who could develop HIV specialties and be better able to compassionately understand and respond to particular patient needs. One focus group participant spoke of the need for AIDS providers to not be culturally competent service sites, but "**culturally affirming**" service sites.

Accessing HIV/AIDS Services in California: A Consumer Perspective Part II

Participants in the statewide focus groups frequently cited **staff turnover and lack of consistent contacts** within service organizations as a major service barrier. Consumers spoke of their deep frustration as they gradually came to trust or respect a specific case manager, physician, or mental health professional over time, only to have that staff person either leave the agency abruptly, or find themselves assigned to a different professional, often on a seemingly arbitrary basis. Focus group members consistently stressed the importance of having **one identified contact over time** in a given agency, particularly when that individual was one that the consumer knew and trusted, and who related to his or her ethnic, social, and lifestyle background. Conversely, consumers also noted the difficulty of being compelled to receive services from a professional they did **not** trust or respect - usually because they believed the professional did not trust or respect **them** – instead of being allowed to request a new provider whom they believed would be more understanding of and responsive to their individual needs.

- In order to **reduce cultural service disparities** within each region of California, local planners and providers must begin by identifying the specific **disparities in the cultural competency of care for racial and ethnic populations in each region.** This process must be followed by activities that develop **key indicators** to gauge progress and assist in making changes and corrections; select the matrix of **core services** to be applied;

develop the specific **service partnerships and access points** that will best address local needs in each area; and identify **complementary funding** to support existing and new services and service models.

- The definition of "quality care" for persons with HIV/AIDS must include **cultural competency** and **accessibility**, including linguistic as well as physical access.

Day Services and Respite Care

- **Day and respite care services** provide critical opportunities for socialization and one-stop service access for persons living with HIV/AIDS, while offering an opportunity for caregivers to access supportive services vital for their ability to provide long-term support to their loved ones.

- However, respondents note that **licensed day care facilities** are virtually non-existent in most communities, particularly in rural areas, and many respondents point out particularly the lack of **licensed, short-term drop off day care facilities** at which PLWH can spend a day or afternoon with no prior notice required.

- The need for expanded day and respite care also points to the need for more general support for **caregivers of persons with HIV/AIDS**. This is a gap in the system that leads to burnout and to the dissolution of support systems for PLWH.

Promoting Innovative and Emerging Models of Care: The Men's Service Network

The **Men's Service Network** in Alameda County is an innovative health collaborative between seven agencies serving high-risk and/or HIV-positive men, especially African American and other ethnic populations, as well as their partners. Services include medical assessments, screening tests, substance abuse treatment, case management, acupuncture for detox and stress reduction, methadone treatment, detox from alcohol or other drugs, residential treatment, transportation, vocational workshops, and health education.

Dental and Oral Health Care Issues

- Questionnaire respondents and focus group participants consistently identify a serious shortage of **oral health care** for persons with HIV/AIDS across all regions and populations. Many private sector dentists are still reluctant to care for persons living with HIV/AIDS, while Part F – Dental Reimbursement Program funds fall far short of meeting actual needs. Some respondents suggest addressing these issues by creating a statewide mechanism for recruiting oral health dentistry fellows, and by emphasizing dentistry as a topic to be covered by the AETC's provider training activities. Others suggest making new funds available to expand and create new dental and oral health services for persons with HIV/AIDS through existing Ryan White Titles.

Direct Emergency Financial Assistance

- **Direct emergency financial assistance** offers a vital lifeline for persons living with HIV/AIDS who are facing personal financial crises or temporary income shortfalls. Assistance for critical emergency needs such as utility payments and rental payments to prevent eviction preserve health by allowing persons with HIV/AIDS to remain in a stable, home-based setting that is essential for drug treatment adherence. These services are also extremely cost-effective in the long run, saving dollars to the service system that would be needed for services such as housing placement and shelter costs.

Employment Development, Placement, and Training Issues

> ***"The income caps that they have on receiving some services are way too low….With our rising utility rates, gas rates, and rent going up, I really think that the caps on these income levels need to be moved up at least $100 a month, if not more."***
>
> - Matt, Person Living with AIDS
> San Diego Consumer Focus Group

- Many people with HIV/AIDS are experiencing improved health benefits as a result of combination therapies, and are considering **returning to work and employment or working for the first time** as a serious life issue. This is becoming more true as PLWH realize that having a larger income could help provide an improved standard of living in an environment in which housing, utilities, food, and transportation costs are rising. However, PLWH face several significant barriers – and have some critical needs – related to this decision. Many PLWH with insurance, for example, are concerned about losing health benefits if they resume employment, or of becoming ill and once again finding themselves unable to work. These consumers are in need of significant legal and benefits assistance - ideally through trained benefits counselors and/or through trained case managers - to help them make this decision realistically.

- PLWH need expanded work and volunteer opportunities which make allowances for those with fluctuating health and energy levels. Such employment programs would ideally be linked to existing opportunities through the various federal, state, and local agencies that focus on rehabilitation and employment development. Both men and women with children also need access to subsidized child care services to allow them to return to a full or part-time job. There is a serious need throughout the state for expanded vocational habilitation and rehabilitation programs; for new employment placement and assistance programs within community-based agencies; and for programs to orient and train business owners and employers about the specific issues involved in having a person with HIV/AIDS on the workforce.

- Consumer focus group participants pointed out the fact that the currently system often actually **creates an incentive to stay poor,** since going back to work creates its own set of problems in paying for services as part of the 'working poor'.

> ***"I want to go back to work, but as a result of my [long-term] disability I'm now a dinosaur. I have no computer knowledge, and I don't have anyplace to go to get trained to work on a computer."***
>
> - Alan, Person Living with AIDS
> Eureka Consumer Focus Group

> ***"Going back to work? That's a wonderful idea – I think that's great. But for some of us who have problems with the different medications, it's a different story. I'd love to go back to work, but I don't know how that combination of drugs is going to affect me right now, and I have to go every 15 minutes to the bathroom because of my diarrhea, that's not going to keep me working long…I've been on four different combination drugs within the last two years, because they have made me sick, or I've started the side effects, and there is not way I can go back to work. There just isn't. And it's not because I'm lazy or I don't want to work – I've worked all my life."***
>
> - Philip, Person Living with AIDS
> Eureka Consumer Focus Group

Food and Nutrition Services

- As the most basic and elemental of all human needs, **food services** are a critical and ongoing need for low-income persons living with HIV/AIDS in California. This need increases as the population of PLWH becomes increasingly impoverished and in need of longer-term support and care. Ensuring access to high-quality foodstuffs - including high-calorie nutritional supplements, home-delivered meals, vitamins, and packaged and prepared foods - is essential for maintaining and prolonging the health status and life expectancy of persons living with HIV/AIDS, and are a necessary pre-condition for ensuring the ongoing effectiveness of HIV-related treatment therapies. Food services must be comprehensively available in California to ensure both that **no** person with HIV/AIDS ever goes hungry. Both pre-packaged foods and prepared meals must also be available in forms fully consistent with dietary needs and restrictions, cultural preferences, and religious beliefs.

- **Nutritional counseling services** remain an essential tool to help PLWH deal with lipodystrophy syndrome and other complications related to poor diet and long-term HIV side effects. There is a particular dearth of such services in Spanish and in Asian/Pacific languages in California.

Harm Reduction Services

- In general, the term **harm reduction services** refers to any intervention that seeks to minimize the harm done to an individual – in the sense of reducing the specific health risks to an individual – by reducing risk behavior **in any way possible**. The term, however, can have different meanings in different settings, and for different populations. For a person who is unable or unwilling to stop using illicit substances, for example, harm reduction might consist of attempting to get the person to use a less harmful drug, rather than refusing services if drugs are not given up altogether. For persons engaging in risky sexual behavior, harm reduction might consist of trying to get the individual to have sex with fewer sex partners, rather than using a condom with every sexual encounter. Harm reduction provides an alternative to an "all or nothing" approach in which persons engaging in risky behavior must either give up all aspects of that behavior completely, or be denied access to any prevention or risk-reducing interventions.

- Respondents and consumers alike agree that increased **harm reduction** services are needed at all levels – particularly **needle exchange programs** through which injection drug users have access to clean needles every time they use drugs. Harm reduction services should be more commonly incorporated into other HIV/AIDS service and care modalities, so that consumers are not unnecessarily lost to the system. However, providers are coming to learn that the quality and nature of harm reduction services can have a significant impact on their effectiveness. In the words of the San Francisco EMA response, "Harm reduction involves meeting clients where they are, and providing them with what they need to take care of themselves and minimize harm due to drug use without being judgmental, demanding sobriety, or making assumptions about their ability to care for themselves." In this sense, harm reduction providers offer a vital point of entry into the overall continuum of HIV/AIDS care, and must be fully integrated with existing HIV-related providers and systems.

Promoting Innovative and Emerging Models of Care: Integrated Programs in San Francisco

In San Francisco, new models of care are being developed to help stabilize individuals with complex, multiple issues so that they can improve their quality of life and access services. These programs focus on integrating disciplines, taking services to where people are, and using harm reduction principles. The new **Action Point** adherence support program, for example, targets multiply-diagnosed, homeless, or marginally housed PLWH and provides treatment advocacy, case management, and other services. New transitional case management programs work with **PLWH in the state prison system** before they are released, linking them to housing, medical care, case management, and other services in the community once they are released. The **Integrated Service Providers** program combines medical care, housing, case management, psychiatric consultation, and peer and treatment advocacy into culturally appropriate, accessible service models.

- Adherence to drug treatment regimens poses a particular challenge to **active substance users.** Wherever possible, these individuals must be supported in learning about and complying with complex drug regimens regardless of their current drug use profile, and should be provided with access to medical care, social services, and comprehensive treatment alternatives at all levels.

Hepatitis C Issues

- **Hepatitis C** is increasingly recognized as a co-morbidity with HIV. As many as **80%** of all injection drug users in California may already be infected with hepatitis C. Services are needed to provide information, medication, and adherence support for PLWH with hepatitis C, as well as prevention resources and education to PLWH at risk of infection. Co-infection with hepatitis C has made many PLWH unable to take or tolerate new treatments, and has led to the need for extremely complex treatments such as liver transplants. Many rural providers are already feeling the lack of qualified gastroenterologists to treat patients with hepatitis C. These problems will create significant new burdens for the health care system as problems associated with advanced hepatitis C begin to manifest themselves later in life. These costs musts be carefully explored and analyzed, so that their long-term impact on the care system can be anticipated, and appropriate funding streams and service approaches can be developed and implemented.

HIV Case Reporting and Confidentiality

- Virtually all respondents identify as a significant barrier the fact that HIV has historically **not been reportable** in California. Non-reportability has limited our ability to obtain a more accurate picture of the true dimensions of the HIV/AIDS epidemic, and has reduced the system's capacity to better identify the scale and nature of the presumed escalation in HIV prevalence among populations such as adolescents and young adults. Lack of reporting has also made it impossible to compare CARE Act populations with populations receiving medical care elsewhere within a given region.

- HIV reporting – currently being implemented in California – will allow providers, regions, and systems of care to better monitor local changes in the epidemiology of HIV, and will enhance their ability to target resources to the populations most affected by the disease and to measure program effectiveness. However, it is important to note that HIV case reporting will still provide us with data that is **only** specific to those who voluntarily seek HIV testing, and will **not** provide us with either a full or comprehensive picture of the full scope of the HIV epidemic in California. While case reporting will improve our overall knowledge and understanding of trends in the epidemic, our ability to utilize HIV case data to reliably plan for trends in HIV/AIDS care and treatment will remain dramatically limited.

- Some consumers also remain concerned about preserving the **confidentiality** of their HIV status. As California moves toward HIV reporting, it will be increasingly important that consumers know that their name is not attached to HIV case reporting and that their privacy is being protected. New consent forms will need to be developed that clearly

inform clients that their case of HIV infection **will** be reported if they test positive. All consumers must also receive comprehensive information regarding all HIV services for which they are eligible at the time of diagnosis.

- This is also an issue related to the data collection process required to develop unduplicated client reports and other evaluation measures. The currently proposed HIV reporting system of using the last four digits of an HIV-positive individual's social security number as a unique client identifier was extensively discussed in meetings of the service provider group. Most jurisdictions support a name-based system, which has also been determined by the State to be the most reliable. However, some jurisdictions also continue to have questions regarding confidentiality. As the San Francisco EMA response states, "Fear of disclosure of HIV status can keep PLWH from accessing the services they need."

Home Health Care Services

- **Home health care services** are a vital link in the continuum of HIV/AIDS care, providing homebound persons living with advanced HIV disease access to high-quality personal care and monitoring, while helping maintain dignity and independence in the face of a debilitating, life-threatening illness.

- Many respondents note, however, that limitations in reimbursement levels for both Medicare and MediCal patients have resulted in many **home health care providers** going out of business, leaving seriously ill and home-bound AIDS patients with diminishing levels of service.

Accessing HIV/AIDS Services in California: A Consumer Perspective Part III

Some participants in the statewide consumer focus groups spoke of a lack of **leadership development** opportunities for persons living with HIV/AIDS. Both men and women living with HIV/AIDS believed that they could more effectively use their time and energies in helping increase public awareness and visibility of HIV/AIDS, or in helping advocate for specific changes or improvements in the overall continuum of care. However, opportunities to develop leadership and involvement skills were rarely available, and focus groups members spoke of the difficulty involved in identifying appropriate volunteer or advocacy positions within their given community or region.

Housing, Homelessness, and the California Energy Crisis

- **Housing** is a basic human need that should be available to all people. For those living with HIV, the lack of safe, stable housing poses a significant threat to health and quality of life, and is a barrier to both adhering to medication regimens and to accessing other essential services. The housing crisis in California's urban areas in particular is also believed to be driving many low-income consumers into substandard housing, or forcing them to move to rural areas farther away from established HIV service centers.

- The expanded availability of **new, affordable housing** would be the most important single step in helping alleviate the state's housing crisis for people with HIV/AIDS, as would public funds to enable people with HIV/AIDS to stay in their housing (eviction prevention) or access housing if they are homeless. Questionnaire respondents and consumer focus group participants both noted the need for more **transitional housing** for recently incarcerated persons with HIV; more **supportive housing** for persons with substance abuse issues and mental illness; **subsidized housing** for individuals and families living with HIV; and **long-term residential care** for persons living with AIDS dementia.

- Housing services for persons with HIV/AIDS must encompass a **full continuum** of options, ranging from emergency to permanent housing, including housing for families with children, and housing with supportive services included.

> ***"The chief problem that I've found with accessing services is bureaucratization and overlap. Things get red-taped to death, and then services overlap and you have to do things two and three times that you should only have to do once."***
>
> - Tony, Person Living with AIDS
> San Francisco Consumer Focus Group

- The crisis associated with the rising costs of housing in California is linked for persons with HIV/AIDS to rapidly escalating **energy and utility costs** throughout the state. In many cases, increased energy costs become the final straw that pushes PLWH into homelessness. Existing subsidy programs must be expanded and new discounting programs must be developed that help people with HIV/AIDS avoid homelessness due to the high costs of energy. High energy and utility costs can also impact quality of care by placing an expanded financial burden on community-based agencies and providers, while the risk of rolling blackouts present serious health challenges for individuals in hospitals and on home-based life support systems.

- In terms of housing, there is a particular scarcity of **housing for women with children,** which requires a separate range of service and support programs in order to be responsive.

- Consumers cited a need for clearer language and orientation in regard to **Section 8,** particularly in order to help landlords not be so fearful of persons living with HIV/AIDS. These same consumers also frequently expressed their frustration and dissatisfaction with the overall quality and condition of available Section 8 housing units.

- Reaching and serving the **chronic homeless population** creates special challenges for HIV/AIDS providers. Intensive case management, long-term residential housing facilities, and long-term mental health services are among the strategies considered essential for getting the homeless into care, and for creating the circumstances to allow them to adhere to medication regimens.

- Providers also note that **bureaucratic procedures and systems** often present severe barriers to quickly and efficiently accessing low-income housing – a problematic issue for persons who are severely ill, debilitated, or homeless.

Immigration Issues and Undocumented Communities

- Historic pressures on **immigrant individuals and families** in California have been exacerbated for both documented and undocumented individuals with HIV/AIDS because of recent immigration policy changes. At the same time, CARE Act providers are too often unaware of the fact that they **can** serve persons who are undocumented, and that these persons can receive CARE Act-funded primary care services.

- Punitive federal and state policies are making it increasingly difficult to gather accurate epidemiological or service data regarding **undocumented individuals**. Undocumented persons – as well as persons who do not precisely know their residency status - are naturally reluctant to disclose or discuss their status, which complicates the task of gathering accurate estimates of either the number of immigrants in need of care, and or on the specific care needs they face.

"Overcoming barriers [to accessing insurance benefits and entitlements] is particularly important in California, given the number of uninsured individuals and the large number of very low-income people and people of color who have difficulty accessing the public benefits to which they are entitled, including Social Security benefits, MediCal, and Medicare. Without coordinated and comprehensive benefits counseling and advocacy, this goal is practically impossible for many HIV-positive people. It is essential that people who are eligible for benefits access and receive them, as this takes pressure off of CARE-funded services. Inability to maximize reimbursements for PLWH also creates gaps in services by reducing the total resources available to pay for care."

- San Francisco Department of Public Health Title I Response

Insurance Benefit and Entitlement Issues

- A significant number of persons with HIV are unaware of the **insurance benefits and other entitlements** for which they are eligible, or have difficulty accessing them. Key barriers include bureaucratic and confusing paperwork; uninformed agency staff; and fear of potential immigration status problems. This problem is exacerbated by the large

number of low-income people of color who are living with HIV/AIDS in California, who traditionally have difficulty in learning about or accessing entitlement and benefits programs, such as the Children's Health Insurance Program (CHIP), which provides critical health benefits for children in low-income uninsured families.

Legal Services

- Comprehensive **legal services** are a critical need for persons with HIV/AIDS, including assistance and education with issues such as benefits, insurance, wills, and power of attorney.

- Respondents noted that HIV/AIDS **legal services** should be expanded to include support with criminal problems, can be an essential link in helping PLWH access the services they need. Parole officers may insist that individuals not visit certain parts of town, even though they may be where HIV/AIDS services are located. Fear of arrest or incarceration may also keep PLWH from interacting with benefits or medical providers – a fact that is particularly true for individuals engaged in sex work. **Legal services** that can address criminal matters for people living with PLWH are a significant gap in the current system, as most legal services are focused on civil matters such as wills.

Accessing HIV/AIDS Services in California: A Consumer Perspective Part IV

Some Consumer focus group participants from throughout the state consistently stressed the frustration and stress resulting from the **extensive paperwork** that persons with HIV/AIDS are often asked to complete and re-complete. Focus group members said that they were often required to complete the **same** client information or consent form with **each** visit to the same clinic or provider, or that they had to complete three or more virtually identical forms on the same day as they moved from service to service within a single agency. Focus groups participants wondered why consent and client background information could not be **centralized** within a given region or locality, so that client consent and basic information could be given only once for each service or agency, and then logged on to a confidential computerized system that could be referenced with each subsequent service visit.

Living Longer with HIV/AIDS: Issues Related to Long-Term Care

- As persons with HIV/AIDS continue to live longer, healthier lives, **new health problems** are beginning to emerge among these populations, including diabetes, lipodystrophy, heart disease, liver disease, and manifestations of Hepatitis C. This creates greater demand for services; presents new challenges related to the expanding complexity of care for PLWH; and highlights the need for cross-training, education, enhanced resources, and more information on medication interactions and metabolic complications. And because persons with HIV/AIDS are requiring services over a longer period of time than in the years before the availability of Highly Active Anti-Retroviral Therapies, resources are needed that are **commensurate with the resulting growth in the overall population of persons to be served.**

- Longer lifespans also create a need for a greater focus on **preventive health services** for persons living with HIV/AIDS, including an expanded emphasis on cardiovascular health, regular procedures such as breast and prostate exams, and expanded and ongoing patient health education in regard to non-HIV health needs. Persons with HIV/AIDS who are living longer are also at risk for diabetes, cardiovascular disorders, and cancers. Primary medical care for these individuals is also more complex and involves more specialty care.

- There is also an expanding group of persons living with HIV/AIDS who are very ill and who may need the support of **residential settings** in order to start on Highly Active Anti-Retroviral Therapy (HAART) with the hope of recovery. While these patients are usually "too well" for the hospital setting or for a hospice setting, their recovery nonetheless depends on having access to a 24-hour nursing supported facility. Hospice facilities do not receive funding for this type of temporary care, which holds the promise of potentially saving many lives.

- In some needs assessments, PLWH expressed the desire for greater opportunities to participate in **community activities**, including more chances to socialize with others with HIV/AIDS, and more options to **volunteer**. As many PLWH's health has improved, these individuals would like to be more active in the community. Many are hesitant to return to work full-time, and see volunteering as a way to be more active while giving something back to their cities and neighborhoods.

- As individuals with HIV/AIDS continue to live longer and healthier lives, a greater preponderance of **aging issues** will be seen and will need to be addressed by provider agencies. These include health, psychological, and social impacts of aging as a person with HIV, including issues of isolation and lack of social interaction among older HIV-affected men who have sex with men.

- As people with HIV/AIDS are living longer and becoming more interested in renewing their social and work lives, a concomitant demand has arisen for **preventive and restorative dental care services**.

Managed Care and Medicaid

- The continued growth of **managed care** has become a significant factor in the ongoing development of the US health services delivery system. An estimated **75%** of all US employees with health insurance are enrolled in some kind of managed care, and nationally, Medicaid is the largest payer of care for persons living with AIDS, providing approximately **70%** of all funds for AIDS care in the United States. Medicaid covers **half** of all PLWHs and nearly **all** children with AIDS.

- Many respondents feel that **Medicaid managed care** has the potential for both positive and negative impacts on the care of persons living with HIV/AIDS. Managed care may facilitate the ability of patients to have a single informed provider coordinating the full range of medical care needed by each consumer. However, fixed per-client caps may provide an incentive to limit access to more expensive care and medications. The implications of MediCal managed care will become even more important if individuals who are HIV-infected but do not have AIDS become eligible for MediCal. Further study is needed to determine the impact of MediCal managed care on the quality of care for PLWH in California.

- Whether or not persons with HIV become eligible for MediCal, many Californians with HIV who lack adequate medical care will still be left out of the CARE Act system because of **income-related limitations**. For example, many consumers on HAART experience severe side effects and are unable to continue working. And even those who are employed often work in industries that do not provide health insurance, particularly persons of color.

- Some respondents believe that PLWH enrolled in **managed care systems** still often have limited or no access to HIV specialists, cutting-edge treatments, and/or effective treatment education.

"On December 17, 1999, President Clinton signed into law the Ticket to Work and Work Incentives Improvement Act. This legislation gives states two new options to offer a Medicaid buy-in for people with disabilities. It also provides $150 million in grants as incentive for states to accept the offer, and creates a $250 million Medicaid buy-in demonstration project for people whose disability is not yet so severe that they cannot work. In addition, it extends for four and a half years Medicare coverage for those in the disability insurance system who return to work. This legislation will make is possible for some PLWAs to join the workforce without losing their Medicaid or Medicare coverage. At the state level, Assembly Bill 155 was signed into law by Governor Davis this past year. It provides that any employed individual whose countable income does not exceed 250% of the federal poverty level and who is disabled for specific purposes shall be eligible for benefits under the MediCal program, subject to payment of premiums. This law will also enable more individuals to take a job without fear of losing their MediCal benefits."

-Orange County Health Care Agency Title I and Title III Response

Mental Health and Counseling Issues

- **Mental health therapy**, both individual and group, and **crisis mental health services** are needed by people with HIV/AIDS to maintain and improve their quality of life, and to help them access full medical care. Mental health services, however, are underfunded in California, and it is extremely difficult for poor or uninsured persons to

access mental health services in this state. Even for those few clients who have private insurance, mental health benefits are not included or are limited, and co-payments are required. In addition, some regions say they are seeing an increased proportion of new consumers with a history of **serious mental disorders** or with current problems that require **psychiatric intervention,** which stretches further existing resources. In addition, for those few consumers who have private insurance, mental health benefits are often either not included; are extremely limited; or require large co-payments.

- There are very few psychiatrists in California who speak either **Spanish or an Asian/Pacific language**. Mental health education and the availability of native language services are essential in HIV care for multiple-diagnosed persons. In addition, there are wide differences among ethnic and cultural groups regarding what precisely constitutes mental health, and of what an individual's specific mental health issues and needs are. These differences must be respected by providers, and necessitate strong culturally competency in both the offering and provision of care. New models must also be developed that offer mental health care and services in newer, more culturally responsive formats.

- The state's current ADAP formulary should be expanded to include a wider range of **psychotropic and other mental health-related medications** that help mentally ill PLWH cope with their lives and maintain themselves on drug therapies.

> ***"I wish mental health had the same amount of emphasis that medical health has. They seem to treat the medical health, but the mental health that is so important to be able to take our meds and just to feel good is always placed second, or third, or ignored."***
>
> - Terry, Person Living with AIDS
> San Diego Consumer Focus Group

- Some respondents identify a need for **long-term AIDS dementia care**, including a need for both **in-home** and **out-of-home** care services. At the present time, few treatment facilities or long-term care programs will accept AIDS dementia patients, and MediCal does not reimburse for this long-term care need. AIDS dementia patients are also not accepted in Alzheimer's treatment programs due to a lack of reimbursement, and a fear of the reactions of families of elderly patients. This issue is closely related to the need for more widely available **long-term mental health services** for persons with AIDS who are living longer thanks to the success of HAART.

- Consumer focus group participants with children spoke of the need for **mental health services for children under the age of 12,** in order to help them cope with having a parent with HIV, or with being HIV-affected themselves. Most participants felt that this need had not yet been considered by most community-based HIV/AIDS organizations.

Multiple-Diagnosed Populations

- As expanded outreach efforts are increasingly successful, providers are seeing more and more **multiple-diagnosed** clients who are affected by both HIV and by mental health and/or substance addiction problems. (Consumers with HIV and either mental health or substance addictions programs are called **dual-diagnosed**, while individuals affected by all three issues are **triple-diagnosed**.) These consumers have complex needs that cannot often be addressed by conventional HIV service structures, and that require extremely close coordination among service providers. Some questionnaire respondents believe that multiple diagnosed populations are best served by specially trained Masters-Level Social Workers (MSWs) who are specifically focused on multiple diagnosed individuals, and who have relatively small caseloads to deal with these populations.

- Multiple diagnosed populations can impact the quality of care across an entire service system by drawing a high proportion of service and staff resources for a small number of consumers. Respondents call for new systems of **integrated funding** among HIV, mental health, and substance abuse funders in order to support these services within a unified framework, and for the development of **comprehensive systems** to address the multiple needs of these consumers across a wide range of service categories. Respondents are particularly concerned that many multiple-diagnosed persons may "slip through the cracks" as health systems focus more closely on cost-efficiency and cost savings in light of managed care.

> ***"It is axiomatic now that HIV is only one of an array of diagnostic labels that many HIV-positive persons carry. Mental health and substance misuse are just two of many other challenges faced by people with HIV. Services to manage these conditions are fragmented, and there are frequently barriers to accessing these services, such as waiting lists, or a lack of services in a given region. Where, for instance, does as undocumented transgendered Spanish-speaking Latina with a history of clinical depression, lengthy criminal record, homelessness, cocaine use, and HIV infection begin? (We have 12 such clients in our clinic.) HIV-dedicated medical services are unprepared to meet the financial and high-management challenges presented by such clients, and traditional mental health and substance misuse management models are unprepared to meet the challenges presented by HIV and HAART. These services must be integrated."***
>
> - Northeast Valley Health Corporation Title III Response, Panorama City

- So-called **stabilization services** encompass a wide range of services from housing to mental health to case management. Stabilization services can play a major role in

helping multiply-diagnosed individuals with complex health and service needs stabilize their lives so that they can improve their quality of health and gain the maximum benefit from medical care and treatment. This approach involves integrating several disciplines and taking services to where clients are. However, stabilization services are also relatively expensive, and require case management support that is extremely labor-intensive. In addition, for those clients who are homeless or marginally housed, it involves recognizing that safe, stable housing is a basic human need, and lack of housing is a severe health hazard.

Peer Advocacy Services

- **Peer advocacy services** – through which trained individuals provide direct service, support, and/or assistance to persons living with HIV/AIDS from comparable or compatible sociodemographic backgrounds – can serve as an essential component within a comprehensive continuum of HIV/AIDS care. Respondents believe, however, that inadequate resources exist to support peer advocacy services, which can be essential in making persons living with HIV/AIDS feel comfortable within service systems, and which can facilitate linkages between primary care, medications, and supportive services.

> ***"I'm one of those scared people. I'd rather stay home and isolate in my apartment. In fact I did that for five months - for five months this last year I was in my apartment. I didn't want to leave, I didn't leave, because I was too scared of people. I didn't make phone calls, I was sick, and I thought, "I have AIDS – and nobody wants to deal with anybody with AIDS, not even the organizations dealing with AIDS want to hear people with AIDS saying the same things over and over again."***
>
> - Anthony, Person Living with AIDS
> Eureka Consumer Focus Group

Perinatal HIV Transmission

- Efforts to interrupt transmission of HIV from mothers to children have effectively reduced this risk, and fewer children are becoming infected with HIV. But perinatal transmission continues among women who do not access prenatal care or accept testing. Many women across the state, especially those who live in poverty, and those who are concerned with substance use or immigration status, are still not accessing prenatal care, and miss the opportunity for HIV testing during pregnancy. Prenatal providers continue to need education to offer HIV education, testing, and interventions designed to reduce transmission. Labor and delivery sites need increased capacity to respond urgently by offering rapid testing to women who have not tested or sought prenatal care, and through obstetrical interventions designed to reduce mother to child transmission.

Poverty as a Public Health Issue

- **Poverty** leads to significant disparities in access to care and to significantly diminished health outcomes, and is increasingly recognized as an important public health issue both in general and in relation to HIV in particular. The majority of persons with HIV/AIDS in California are living in poverty, and many respondents point out that poverty is in many ways the most significant and central health threat in the lives of most CARE consumers. Poverty is a consuming condition that often draws attention and focus away from health preservation and life improvement. Poverty also creates barriers to accessing services, and creates additional needs for so-called 'survival services' such as food and housing. As HIV/AIDS increasingly impacts low-income and impoverished communities, the need to support basic services will increase, placing an expanding burden upon the system. Responding to the basic needs of newly-diagnosed persons with HIV living in poverty will also become an increasingly important issue.

> ***"Poverty is a public health issue. Poverty is a associated with a lack of stable housing; families and individuals living in substandard housing in higher crime areas; homelessness; insufficient food to maintain adequate nutrition; lack of health insurance to access medical and dental care; people unemployed or working in minimum wage jobs; single-female-headed households; inadequate transportation; and lower educational attainment. People living in poverty are frequently found in community in color, [in both] rural and urban and suburban areas…[and] tend to seek health care on an emergency or urgent care basis in more acute stages of their disease. They also frequently lack accurate information on available services. Life under these conditions can be overwhelming to some, resulting in higher rates of mental illness and substance abuse. All of these conditions should be considered by public health managers in the planning, program design, and delivery of services."***
>
> - San Bernardino County Department of Public Health Title I Response

- Some respondents suggest the formation of **new partnerships** between HIV agencies and traditional poverty organizations and community groups in order to expand and deliver services for both populations.

Prevention for HIV-Positive Persons: A Critical Link in the Chain of Care

- As people are living longer with HIV, effective and comprehensive **prevention services for people living with HIV/AIDS** are an indispensable element in the continuum of care for PLWH. However, it is also an element that providers acknowledge has frequently been ignored or overlooked in some areas and jurisdictions.

- Questionnaire respondents agree that prevention services for persons with HIV/AIDS must be focused on empowering persons with HIV to protect themselves and others, and must be provided in culturally appropriate, respectful ways which take into account the emotional and mental health aspects of HIV/AIDS. Prevention messages and interventions should be tailored to PLWH distinct and separate from prevention messages and interventions for negative individuals.

- For some respondents, the growing awareness of prevention for positives issues calls into questions the formal and in some ways artificial distinctions we have drawn between HIV care and prevention in general. Just as prevention for positives must be fully coordinated and integrated with prevention for HIV-negative persons, so care and prevention services must be more fully coordinated and integrated at all levels, and wherever possible.

"Growing numbers of men and women are living with HIV for a much longer lifespan, and are living healthier, more sexual lives in the process. Many are beginning to consider and explore the possibility of new intimate relationships for the first time in many years, and need support and advice on how to discuss and maintain safe behavior with their partners. New evidence is also beginning to point to an increase in sexual risk-taking among both HIV-positive and HIV-negative persons….It is critically important to support the development of prevention efforts that help meet the unique prevention needs of persons living with HIV, and that offer sensitive, compassionate, and respectful interventions that give HIV-positive persons the skills and support they need to enact and maintain the safest possible lifestyles for themselves and others."

- From "New Hope, New Challenges: A Profile of the HIV/AIDS Epidemic in California", Northern California Grantmakers AIDS Partnership California, September 2000

Primary Medical Care and Drug Therapies

- Virtually all cross-cutting needs assessments in California rank **primary medical care** as the most critical priority service areas for persons living with HIV and AIDS. Primary ambulatory medical care services seek to monitor and maintain the client's overall physical health, and to link the patient to emerging treatments, therapies, and health care approaches. Comprehensive primary care services must be accessible and affordable for all persons living with HIV/AIDS in California, regardless of changes in the nature and scope of the HIV-affected population, or of medical diagnosis and treatment now and in the future.

- Drug failure occurs in about **half** of patients using combination therapy, and it is estimated that **over 90%** of those cases are due to **drug adherence issues**. Adherence problems are not unique to HIV. Rates of adherence to medication for other diseases such as asthma, diabetes, and heart disease have been reported to be between **20% and 50%**. However, adherence to HIV regimens is particularly problematic because of the number of pills that must be taken, the complexity of drug regimens, the incidence of side effects, dietary restrictions for some medications, privacy concerns, and the occurrence of complicating factors such as mental illness, substance abuse, and physical problems.

- **Treatment education and pharmaceutical consultation** remain critical needs for persons with HIV/AIDS, both to help them adhere to treatments, and to ensure that they are aware of the full range of treatment options available to them. In some regions, resources to support treatment education are diminishing, rather than increasing in the face of continual development of new treatments and treatment strategies. Consumer focus group participants felt that there was often too little attention paid to fully explaining the consequences and potential benefits of each medication regimen to patients, and that medical professionals often did not explain or understand the perils and problems resulting from specific **interactions** of medications with either other drugs or with pre-existing patient medical conditions.

- New, successful **drug therapies and combination treatments** have created a parallel need for more sophisticated, expensive laboratory monitoring tests in regard to Highly Active Anti-Retroviral Therapy (HAART), and for more frequent visits per patient. This creates a need for additional resources for Ryan White-funded primary medical care providers throughout the state.

> ***"Information about treatment and care is a critical need for many clients, and a significant barrier to care. Consumers felt that medical providers did not spend enough time explaining treatments and treatment options to them, and that although there was a lot of information available, sometimes it was overwhelming, and people had difficulty knowing which sources to trust. In particular, some people reported getting inconsistent and conflicting information from their providers about their treatment options. Given the rapidly changing treatment options, this is not surprising. Information needs to be distributed in easily understandable formats, and providers need to be able to take the time to talk to their patients to ensure they understand everything. In addition, treatment advocates and peer advocates can be useful in helping consumers understand the information and choices they have. Accurate, reliable information to dispel myths and misperceptions, such as the belief that HIV does not cause AIDS, must also be made widely available."***
>
> - San Francisco Department of Public Health Title I Response

- The issue of **structured treatment interruptions** for PLWH needs increasing study and attention. Consumers need information and help in order to make informed choices about treatment "holidays", while providers need education and training on the careful application of structured treatment interruptions and other cutting-edge treatments. The need for continually updated information on this subject mirrors the need for updates on all areas related to HIV treatment that will continue to emerge over the foreseeable future.

- The increasing pressure to provide more comprehensive primary medical care services for people with HIV/AIDS can in part be addressed by **expanded availability of services hours** after regular business hours and on weekends and holidays, in part to reduce use of hospital emergency rooms.

Research and Clinical Trials

- Advocacy that assists consumers in identifying and entering appropriate **clinical trials programs** is a continuing need. It is difficult for consumers to research and access clinical trials programs on their own, and most consumers need the assistance of an **advocate** in order to identify the most appropriate programs, and to gain access where access is limited.

- Expanded clinical trials programs focused on **women and young people** are identified by respondents as being a critical need. Respondents also note that many clinical trials programs are not accepting patients who are monolingual Spanish-speakers because these trials programs do not have staff who speak Spanish, or do not have consent forms available in Spanish.

Promoting Innovative and Emerging Models of Care: The HIV Clinical Care Coordination Panel

In order to meet the needs of multiple diagnosed clients, the **HIV Clinical Care Coordination Panel** in Sonoma County brings together public health officials, medical care clinicians, mental health specialists, substance abuse providers, client advocates, and case managers to review complex cases and offer solutions. The Panel uses an innovative, multidisciplinary approach to examine each client's individual situation, and prepares a service plan that can help clients access services and adhere to complex medication regimens. A person with HIV serves as a consumer representative on the Panel, and additional expert consultation is added as needed. The Panel is supported through CARE Act funds, the County of Sonoma Department of Health Services, and various community-based nonprofit service organizations.

Rural Service Issues

- Respondents throughout the state stress the ongoing difficulty of forming and providing a full continuum of care to HIV-affected men and women in **isolated rural communities.** These problems relate to both the dearth of qualified providers in rural areas, and to the great distances consumers must travel in order access individual services. Some communities have developed relationships with HIV specialty physicians from urban areas who spend a designated period of time once or twice a month in rural clinics, seeing patients on an appointment-only basis. But these clinics often lack state-of-the-art instruments and testing equipment to allow adequate on-site diagnosis and treatment, and that nearly always preclude referrals to **medical specialists** to deal with specific health and medical problems. Even when services are available in rural areas, they are simply **not** accessible to consumers who are too sick to travel to these service sites, or who lack transportation options and subsidies to consistently keep appointments. As the Sacramento Title I response, notes, "Because California is a state with such a diverse geography, rural health care issues must be addressed with collective thought and creativity."

- Focus group participants and respondents spoke of the need for more **sensitive and understanding rural physicians,** particularly when dealing with communities of color and with gay and bisexual men. Many of these individuals wish their HIV status to remain **confidential** because of the stigma and hostility they fear they will face, and are mistrustful of the medical community's commitment to maintaining this confidentiality. Many gay and bisexual men living with HIV said that they feel they must remain closeted in rural areas, because of a lack of supportiveness, and were afraid of having their sexuality exposed by medical providers and clinics.

Accessing HIV/AIDS Services in California: A Consumer Perspective Part V

Many consumer focus group participants point out as a severe gap in CARE Act-funded services the continued shortage of **experienced, HIV-specialist private physicians** to serve CARE Act patients, especially in rural areas of California. Focus group participants cited many examples in which they were assigned to a physician who was totally unaware of the complexities of HIV/AIDS, or who had never before seen or treated a patient with HIV, or who was not up-to-date on the latest developments in AIDS-related medications and treatments. Such encounters frequently created a situation in which the patient was mistrustful or anxious in regard to the provider, or in which the patient chose not to follow physician orders at all and instead attempted – often in vain - to find a more experienced provider in their region. This situation speaks to the need for **expanded provider training** on HIV issues – especially in rural areas – and for the importance of identifying and recruiting **HIV- experienced physicians** to join CARE Act-funded health systems.

Substance Use and Addiction Treatment Services

- In part because of its close links to HIV infection, the need for the broadest possible range of **substance abuse and addiction treatment and recovery programs** is seen as critical among both providers and persons living with HIV/AIDS. These programs must cover the full spectrum of treatment approaches, and must respond to the widest possible range of consumer needs, recognizing in particular the wide range of drugs of choice and broad range of treatment modalities available to treat addiction. This includes not only residential (medical) and non-residential detox and recovery programs, but programs available in a range of different languages, and programs that are sensitive to the needs of populations such as women, young people, communities of color, and persons with divergent sexual orientations.

- Questionnaire respondents noted a dearth of **residential substance abuse treatment** programs for **women with children**. Meanwhile, consumer focus group participants spoke of the need for a wide range of services to support **single mothers in recovery**, including child care services while attending AA and other support group sessions, and respite care during times of severe stress or anxiety.

- Some respondents note that their needs assessment processes have identified a gap in transitional care from **detoxification** to **outpatient treatment services** that is not covered by existing local resources. This gap will become magnified over the coming years as outreach brings more active substance users into treatment. The lack of appropriate "after-care" contributes to a high rate of recidivism in substance abuse treatment programs, while unclear and conflicting regulatory provisions of federal, state, and local funding sources cause additional barriers to providing service "on demand".

- There is a severe shortage of **non-methadone detox services** for individuals addicted to serious substances other than heroin, such as methamphetamine and speed.

> ***"We have an increase in the heterosexual population [living with HIV], and while you have some providers who are delivering key services, for the heterosexual populations, there is a stigma that certain agencies are gay-centered, and they are very hesitant to go and get those services, so I think people are staying away because of the negative stigma…This relates to both homophobia – the heterosexual population not wanting to go and be around the gay population – and then you have a lot of gay people who are really uncomfortable with, say, the families bringing in children, where the children want to be playful, and that's seen as being disruptful to people who are sick…So we need to address those issues so that everyone is comfortable getting the services they need."***
>
> - Jeff, Person Living with AIDS
> Long Beach Consumer Focus Group

- Some respondents note that there is also a significant lack of substance abuse programs specifically designed to serve **young people** effectively.

- Some respondents indicated that the recent passage of **Proposition 36** in November 2000, with implementation in July 2001, will have the welcome outcome of reducing the number of substance users who are sent to prison, and increasing the number of substance users who are referred to drug treatment programs appropriate to their needs. However, it may also have the effect of increasing pressures on already overburdened treatment and recovery systems, and may reduce the number of drug treatment slots available to persons who were **not** referred to drug treatment as a result of the Proposition 36 mandates.

Transgender Service Issues

- Continued discrimination against **transgender individuals** puts these individuals at increased risk for HIV and makes it difficult for them to access many services. In San Francisco alone, **35%** of all male-to-female transgender women are estimated to be currently living with HIV, yet access to comprehensive services throughout the state remains an issue. As the San Francisco EMA response notes, “There are still no state laws banning discrimination against transgender individuals in housing, employment, and other areas, and recent studies in San Francisco have shown extremely high seroprevalence rates and risk behaviors in the transgender community, and have also shown that discrimination is a barrier to care.” In addition, many providers are unfamiliar with or uncomfortable serving transgender consumers, creating significant gaps in the system of care.

- State and federal insistence on use of the categories of "male" and “female" in collecting HIV/AIDS case data forces epidemiologists to under-report or mis-report the rate of HIV infection among transgender individuals in state and federal reports, and creates an unnecessary and discriminatory barrier to full and accurate reporting on the true nature of the HIV/AIDS epidemic among transgender persons. Consistent categories are needed on a nationwide basis to allow for full and accurate reporting of HIV incidence across the full range of gender categories.

Translation and Interpretation Services

- As noted above, language and cultural barriers create significant problems for PLWH whose primary language is not English, particularly in terms of the lack of professional and paraprofessional providers who are bilingual in either English and Spanish or in English and one or more Asian/Pacific languages. In addition to the huge number of Californians who speak Spanish as their primary language, more than 100 different Asian/Pacific languages and dialects exist in our state. **Translation and interpretation services** provide an essential means for providers who do not speak the client's primary language – particularly medical care professionals – to listen to and learn from people living with HIV/AIDS, to and communicate important medical and support information that can enhance both the quality and length of patient life.

- Translation and interpretation services, however, must always be **culturally specific,** delivered by individuals who understand not only the patient's language or dialect, but also his or her specific cultural perspectives and backgrounds. These cultural differences can often impair a clear understanding of a specific question a patient may be asking, or of a specific need for services, despite the apparent ability to track what is being spoken in a literal sense.

Transportation Services

- Ensuring full access to comprehensive **transportation services** remains a central need for persons with HIV/AIDS. Transportation is often the only means to ensure accessibly of medical and social services for PLWH, and to support full adherence to treatment regimens. Yet many areas lack adequate public transportation resources or subsidies, while increasing gasoline prices greatly affect the cost of commercial transportation services. Enhancement of transportation services must include both **access** to a full range of transportation options, and **subsidization** of transportation costs, including transportation suitable and accessible to persons with disabilities other than HIV.
- Transportation issues are of particular importance in areas in which PLWH must travel long distances to access care. In such regions, **van-based services** are often the only alternative to daylong bus rides or unaffordable taxi fares. Yet van services are also expensive to provide, and can serve only a limited number of consumers per day, particularly when they must travel a long distance to pick up and drop off each consumer.

> ***"Where I live, to get money for a bus pass, you have to fill out an application that includes a requirement that you write a thing that shows where you've gone to two or three other sources to find a bus pass first, and that you say things like, "I went to the church and asked them to buy me a bus pass; I wrote a letter to this local business to ask for a bus pass, etc."...Well, I understand this is emergency money, but when someone is ill, and they need a bus pass to get to their doctor's, and some of them don't have a lot of reading and writing skills, they don't have a lot of resources to know where to call and check other places....They say, "This has to be the last resort." Well, I wouldn't have come to you if this wasn't the last resort! I think a lot of people find that very frustrating."***
>
> - Angela, Person Living with AIDS
> Eureka Consumer Focus Group

- Transportation is a critical component of the overall continuum of care whose costs continue to accelerate on an ongoing basis. And as the HIV/AIDS service system strives to create expanded and enhanced services to meet the demand for comprehensive systems of care, the demand for expanded transportation services also increases, placing greater cost demands on the system as a whole. These service

repercussions must be taken into account both when planning for and mandating new services within jurisdictions or regions.

Women and Family Service Issues

- In general, both focus group participants and questionnaire respondents felt that a comprehensive continuum of care was less readily and regularly available for **women** than for men. A comprehensive continuum of women's HIV services **must** include women-focused and 'women-friendly' primary/specialty medical care, especially in obstetrics and gynecology (OB/GYN); family planning and prenatal care; mental health services; women-only support groups; child care; transportation; housing; food; and access to public benefits programs. Ideally, this includes the availability of women medical and psychosocial providers from a variety of ethnic and linguistic backgrounds. Many women participants in our consumer focus groups spoke of their frustration with doctors who did not recognize potential HIV symptoms in women, including frequent vaginal infections, or who did not recognize differences in potential medication therapies and prescriptions for women as opposed to men.

> ***"I'd like to see more services for women with children. I work for an agency that works primarily with African Americans, but we have gay, straight – we have everybody there. But I've seen women with children be turned away because they can't attend the nightly group because they have children."***
>
> - Laura, Person Living with AIDS
> Long Beach Consumer Focus Group

- Many providers noted that because women have such specific and distinct needs in regard to HIV/AIDS support and treatment services, the existing male-centered system often unwittingly creates insurmountable **barriers** to women accessing adequate HIV/AIDS care. In many cases, this will require reorganizing existing systems of care to respond to **both** women and men, or, in other cases, creating entirely **new** systems of care that recognize the distinct service requirements of women, and that build service systems and networks consistent with their needs

- Women tend to enter the care system later in the disease process than men, and they often experience severe social isolation; have problems with transportation; and find it a challenge to regularly attend support groups. The **stigma** that still exists regarding HIV/AIDS among women is a further barrier to seeking early intervention and care. Women also risk receiving inadequate care when their individuals needs are not completely or sensitively addressed, or when providers do not acknowledge or take into consideration their various family responsibilities, and how this may affect their ability to access services or follow-through on medical or social service referrals.

- Both questionnaire respondents and consumer focus group participants consistently identified the lack of **licensed, affordable child care** as a serious barrier to accessing care, particularly among low-income women. Most private non-profits have not yet chosen to assume either the cost or the liability of providing on-demand child care

services, and there is a lack of financial support to fund child care services in most regions. Consumer focus group participants indicate a definite preference for a system in which they can identify their own child care providers themselves, and can be **directly reimbursed** for these service costs, such as through vouchers. However, such reimbursement programs remain minimal. Some child care needs are addressed through **volunteer respite care programs** in which volunteers provide short-term child care at the time of client medical or psychosocial appointments, or to give a client 'time off' from the demands of child-rearing. However, these programs are not comprehensive, and cannot meet longer-term emergency or psychosocial needs. Some EMAs note that the implementation of **welfare reform** has resulted in **fewer child care spaces** being available for families with young children in which one or more members is living with HIV.

- One excellent piece of news is that because of the efficacy of new medications in preventing perinatal transmission - and efforts at the federal, state, and local level to encourage providers to offer culturally, linguistically, and educationally appropriate information and counseling to women living with HIV – **perinatal transmission of HIV** has been dramatically reduced in California.

Young People and Adolescents

- As more and more **young people (18 - 24)** and **adolescents (13 – 17)** are affected by HIV/AIDS, it is vital that specialized service continuums be developed and refined for both gay-identified and non-gay-identified youth. This should include programs for testing and outreach that go beyond the traditional prevention education model, and specialized medical care services and clinic times that are tailored to young people and are more easily and comfortably accessible. The continuum also needs to include increased substance abuse service for young adults living with HIV; increased access to specialized mental health treatment services; increased availability of housing, transportation, and social support services; and increased support for young adults transitioning out of incarceration settings.

- As evidence continues to indicate that more **young people and adolescents** are being infected with HIV, it is vital we expand our efforts to encourage and facilitate expanded, voluntary HIV testing by young people. Some questionnaire respondents note that HIV is a particular threat to young people and adolescents who engage in survival sex and prostitution.

- **Specialized prevention interventions** for young people living with HIV/AIDS must also be developed and expanded, particularly as these interventions will require approaches and systems distinct from those focused on HIV-positive adults.

Other Trends and Areas of Concern

- Expanded **case finding and HIV testing efforts** are essential for identifying men, women, and young people with HIV and getting them into care earlier, including people who are both aware and unaware of their HIV status. In Los Angeles County alone, an estimated **18,000** to **20,000** persons are believed to be HIV positive yet unaware of their HIV infection status.

- The rising costs of providing medical care are making it difficult for many providers to continue offering the same high levels of **psychosocial support services** while effectively meeting the ongoing ambulatory care needs of persons living with HIV/AIDS.

- **Family-focused care** remains a pressing need in California, particularly as families experience mounting barriers to accessing care. Families need services that include housing, transportation, child care, and variety of specialized health services, and need all of them to be provided through a **family-centered system of care.**

- There is a strong and continually-expanded need for **social support services** as people with HIV/AIDS live longer, particularly among persons lacking social contact and strong social networks, such as persons in recovery, persons with HIV who have lost a significant other to AIDS, and homeless persons.

- Several consumer focus group participants expressed their desire to have available a **statewide ombudsman's office** which could respond to specific consumer needs and requests that could not or were not being adequately addressed at the local level. Such an office could also help identify consumer problems across different regions of the state, or across a range of disciplines and professions.

- **Heterosexual** participants in our statewide consumer focus groups often voiced their frustration with services that were oriented toward gay and bisexual populations, citing particularly the need for ongoing **heterosexual support groups** in community-based AIDS agencies, and for **heterosexual case management staff** who are aware of heterosexual communities and resources in their respective region.

- The new Ryan White CARE Act reauthorization emphasizes **quality management** issues across all Titles. CARE Act funded entities will therefore be working to develop means to measure the quality of their programs and implementing training systems to improve quality over the coming years. This work will include the need for Title II-funded ADAP participating pharmacies and prescribers to develop quality management interventions.

- There is a need for expanded availability of **volunteers** to assist AIDS service organizations is a critical, ongoing concern. Volunteers provide indispensable support to community-based organizations, and need support and intervention to avoid burnout and turnover. However, paid staff resources are generally required to recruit, train, schedule, monitor, and recognize the contributions of volunteers.

- Enhanced outreach to **faith-based communities** is a trend that will hopefully result in greater awareness of HIV/AIDS in communities, and greater availability of HIV services for members of religious communities throughout the state.
- More resources are needed to allow communities to conduct truly comprehensive and accurate **needs assessments** in their region that facilitate more effective and efficient allocation and provision of services to meet the full range of existing needs. Some respondents also feel that the required timeframes for conducting local and regional needs assessments are too rapid, and that conducting needs assessments for different populations and issues separately limits our ability to get an accurate overview of the entire problem. These respondents recommend one, long-term, centralized needs assessment process that can give us accurate data across the entire spectrum of AIDS care and services.

- In California, decreased revenues for **public hospitals** as a result of the Balanced Budget Act are leading to cuts in services throughout the state. Medicare and MediCal reimbursements have also been cut, and the proportion of uninsured people needing care is increasing. Meanwhile, public health departments are experiencing unprecedented deficits, and are being forced to cut programs serving people living with HIV and AIDS. Additional budget cuts will create gaps by reducing or eliminating critical services needed by PLWH.

Promoting Innovative and Emerging Models of Care: The ARIES Project

In Spring 2000, the Riverside/San Bernardino EMA entered into a partnership with the San Diego EMA, the State of California Office of AIDS, and the State of Texas Title II Program to collaborate on the design and development of a collaborative Management Information System (MIS). The MIS will appropriately collect, process, share, track, and report essential HIV/AIDS client demographic information; and financial, client service, and outcomes data. This innovative approach is known as the **AIDS Regional Information and Evaluation System (ARIES) Project.** The Final Report for Phase I of the three-phase process has recently been completed.

- As government officials, media representatives, and the general public become **less concerned about and focused on the HIV/AIDS crisis**, it is becoming increasingly difficult for service systems to identify non-federal sources of support to fill gaps in CARE Act funding. This puts additional pressure on providers to reduce or eliminate supportive or augmentary services that would formerly have been considered critical, while threatening the overall financial stability of smaller community-based AIDS organizations.

VI. INDEX OF KEY TOPICS

The following is intended to provide a simplified way of locating references to key HIV/AIDS service categories, topics, and issues within the SCSN. **Boldface** page numbers refer to sections in which topic areas are highlighted as either a goal or a special issue area. Non-boldface page numbers cite other mentions of the topic area. We welcome your suggestions regarding enhancements of this section for future versions of the SCSN.

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